

THE PSYCHOSOCIAL EFFECTS OF AIDS AND THE DEVELOPMENT OF IDENTITY AMONGST AIDS ORPHANS

by

BOITUMELO FLORENCE TSHENKENG

submitted in part fulfilment of the requirements
for the degree of

MASTER OF ARTS IN CLINICAL PSYCHOLOGY

at the

UNIVERSITY OF SOUTH AFRICA

SUPERVISOR: Dr M C MATOANE

JULY 2009

I declare that ***The psychosocial effects of AIDS and the development of identity amongst AIDS orphans*** is my own work and that all sources I have used or quoted have been indicated and acknowledged by means of complete references. I also declare that the raw data upon which the results of this study are based is obtainable from the author upon request.

.....

.....

SIGNATURE
(B.F. TSHENKENG)

DATE

SUMMARY

The aim of this study was to explore the experiences of children orphaned by HIV/AIDS and its impact on their identity development.

The qualitative research paradigm was chosen for the purpose of this study. In depth interviews were held with three young adults who lost one or both parents to HIV/AIDS when they were young. Hermeneutics thematic analysis was used to analyse the data.

The study's results identified different psychosocial issues associated with HIV/AIDS which were considered to be an influence in the lives of participants and their identity development. The results indicate that HIV/AIDS still has a strong and negative connotation which influenced the participants' attitude and behaviour, including the development of their sense of identity.

Key terms: HIV/AIDS Impact, HIV/AIDS Orphans, Attitude on HIV/AIDS, HIV/AIDS and Education, HIV/AIDS and Psychological Wellbeing, and HIV/AIDS and Households

ACKNOWLEDGEMENTS

I would like to thank the Lord Almighty for being my strength when I was weak, for instilling hope when I was discouraged and most of all for giving me this opportunity.

I would also like to thank the following people:

- My supervisor, Dr. Matshepo Matoane, for consistently being the voice of reason and wisdom during this process. Her guidance and support made my dream a reality. May God continue to increase her wisdom.
- My husband, Lorato, for believing in me and making it possible for me to achieve this. Your tremendous love and support have been encouraging.
I love you.
- My children, Oamogetswe and Reabetswe-Neo, for being a constant reminder of why I am doing this.
- My Mom. To her I have to say: “The seed you planted is now bearing its fruit. Your hard work and sacrifices for my education were not in vain. May God continue to give you strength”.
- My Mom- and Dad-in-law: I sincerely and truly appreciate your prayers and support.
- My younger sisters, Tsholofelo and Kebaabetswe: Thanks for allowing me to be your example and role model in life. This has encouraged me to want to be a better person and to achieve more.
- All my dear friends: Your support throughout this process has not gone unnoticed. Thank you very much.
- David Letsoalo, the editor of this work, for doing such a diligent and magnificent job.

CONTENTS

1. CHAPTER ONE: INTRODUCTION AND BACKGROUND TO THE STUDY

1.1 Rationale for the study
3

1.2 The Impact of HIV/AIDS on AIDS orphans and other vulnerable children 4

1.2.1 Loss and bereavement
4

1.2.2 Structure of a nuclear family
6

1.2.3 Psychological well-being
7

1.2.4 Education
8

1.3 The impact of HIV/AIDS on Identity Development
9

1.4 Aim of the study
11

1.5 Objectives of the study
12

2. CHAPTER TWO: LITERATURE REVIEW **13**

2.1 Introduction
13

2.2 Definition of concepts
14

2.3	The impact of HIV/AIDS on AIDS orphans and other vulnerable children	14
2.3.1	Loss and Stigmatisation	14
2.3.2	The structure of the nuclear family	17
2.3.2.1	Female- and/or Single parent-headed households	18
2.3.2.2	Child-headed households	20
2.3.2.3	Grandparents as emerging caregivers	21
2.3.3	The impact of HIV/AIDS on psychological wellbeing	22
2.3.4	The impact of HIV/AIDS on education	25
2.4	Theories of Identity Development	28
2.5	Erikson's Psychosocial Theory of Identity Development	34
2.5.1	The structure of personality according to Erikson	34
2.5.2	Personality according to Erikson	35
2.5.3	Stages of Identity Development according to Erikson	38
2.6	HIV/AIDS and Identity Development	39
3. CHAPTER 3: RESEARCH METHODOLOGY		
39		

3.1 Qualitative Research Approach	42
3.2 Rationale for Qualitative Research Approach	43
3.2.1 Postmodernism	44
3.2.2 Social constructionism	45
3.3 Sample for the study	47
3.4 Research instrument	48
3.5 Data analysis using Hermeneutics Approach	48
3.5.1 Familiarisation and immersion	49
3.5.2 Thematising	49
3.5.3 Coding	50
3.5.4 Elaboration	50
3.5.5 Interpretation and checking	50
3.6 Ethical consideration	51

4. CHAPTER 4: RESEARCH RESULTS

53

4.1 Introduction

53

4.2 The results of the study	54
4.2.1 The story of Lucky	54
4.2.1.1 Biographical information	54
4.2.1.2 Family background	54
4.2.1.3 Psychosocial issues	55
4.2.1.3.1 Material support and dependency	55
4.2.1.3.2 Education and outlook on the future	57
4.2.1.3.3 Parental love and care	59
4.2.1.3.4 Isolation and sense of disconnection	61
4.2.1.3.5 Stigmatisation and discrimination	63
4.2.1.3.6 Ego Identity	67
4.2.2 The story of Sibongile	71
4.2.2.1 Biographical information	71
4.2.2.2 Family background	71
4.2.2.3 Psychosocial issues	72

4.2.2.3.1 Material support and dependency	72
4.2.2.3.2 Education and outlook on the future	75
4.2.2.3.3 Parental love and care	77
4.2.2.3.4 Isolation and sense of disconnection	80
4.2.2.3.5 Stigmatisation and discrimination	84
4.2.2.3.6 Ego Identity	90
 4.2.3 The story of Rethabile	 94
4.2.3.1 Biographical information	94
4.2.3.2 Family background	94
4.2.3.3 Psychosocial issues	95
4.2.3.3.1 Education and outlook on the future	95
4.2.3.3.2 Parental love and care	98
4.2.3.3.3 Isolation and a sense of disconnection	101
4.2.3.3.4 Stigmatisation and discrimination	104
4.2.3.3.5 Ego Identity	109

4.3 Researcher's reflection

115

4.4 Conclusion

116

5. CHAPTER 5: DISCUSSION AND CONCLUSIONS

118

5.1 Introduction

118

5.2 Conclusions of the present study

118

5.3 Implications of the study results

124

5.4 The strength of the study

124

5.6 The limitations of the study

125

5.7 Recommendations for future research

125

5.8 Conclusion

126

References

127

Appendix A: Informed Consent Form

139

Appendix B: Research Interview Guide

140

CHAPTER 1

1. INTRODUCTION AND BACKGROUND TO THE STUDY

HIV/AIDS is acknowledged to be an increasing significant humanitarian and development concern across the world. This is particularly the case in the sub-Saharan Africa (UNAIDS, 2006). AIDS is believed to be responsible for the large proportion of death cases in recent studies. Researchers believe it is the leading cause of death since the millennium in many countries. HIV/AIDS is also increasingly seen as a security issue, with serious implications for the well being of individuals, households, communities and states (Pharaoh & Schonteich, 2003). Although HIV/AIDS is seen to be affecting most of the adult population, a growing concern among researchers and analysts is focused on children who will be orphaned following the aftermath of this pandemic.

Some researchers believe that sub-Saharan Africa is faced with the prospect of a growing number of AIDS orphans and other vulnerable children within the context of HIV/AIDS (Pharaoh, 2004). Some analysts have speculated that large numbers of orphans could themselves pose a security challenge because most of these children will require proper care and support from different sectors of the government (Pharaoh, 2004). Institutions from government and the private sector have to be well-prepared to accommodate this crisis in order to assist children who might be affected or infected by this pandemic. However, statistics about HIV/AIDS continue to present a growing concern over these children and their future.

According to the global summary of the AIDS epidemic provided by UNAIDS and WHO (July, 2008), it is shown that sub-Saharan Africa remains the hardest hit by HIV/AIDS as it now accounts for more than

68% of all people living with HIV worldwide. South Africa is also rated among the countries with the highest number of infections in the world; with an estimate of 5.7 million people said to be infected with HIV. It is indicated that in the sub-Saharan region, women are mostly affected as they represent about 61% of people living with HIV. The UNAIDS (2008) report shows that South African young women are also at a higher risk of HIV infection than men. So far, about 3.2 million women from the ages of 15 years and older are reported to be living with HIV. This epidemic has also affected many children. It is reported that the number of children between 0-14 years of age who are estimated to be living with HIV in South Africa is 280 000, while the number of AIDS orphans between the ages of 0-17 years is estimated to be between 1.4 and 1.8 million. It is believed that the high infection rate is likely to result in many orphaned children. About 15 million children worldwide have so far lost one or both parents to AIDS (UNAIDS, 2008). In the sub-Saharan region the number of children living with HIV is estimated at 2.1 million and the number of children who have died from the disease is estimated at 290 000.

According to Barolsky (2003), the HIV/AIDS epidemic will be felt most acutely at the level of families. Of the AIDS-related deaths per year, at least half of that population falls into the 25-44 years age bracket, as it is indicated that the number of adults living with HIV in South Africa is 5.7 million (UNAIDS, 2008). This suggests that men and women are likely to fall ill during the years in which they are likely to have children and raise them. The consequence of this is that it could put them at a risk of not only infecting their offspring but also impeding their ability to care and raise them as desired (Landman, 2002). Pharaoh and Schonteich (2003) concur that as HIV/AIDS epidemic progresses, there might be fewer adults of normal parenting age to care for the children they leave behind. This high infection rate among the adult population

can pose a threat to the lives of many children that might be affected by this pandemic. Landman (2002) believes that with the death of most of the adult population in their parenting years, there is a high possibility of a growing generation of young people left to their own devices with no appropriate parental care, love and guidance, natural affection and role models. It is of great concern that there might be no one to hand down knowledge, experience and, perhaps most important of all, values and morals from one generation to another.

Even though HIV/AIDS is a national and international concern, it is still felt and experienced at an individual level. As a result, the study seeks to understand the individual experiences of those affected by HIV/AIDS. The focus of the study is more at an individual level, which is explained in the rationale for the study below.

1.1 RATIONALE TO THE STUDY

The researcher realised that most attention had been focused on understanding the reasons for the high rate of HIV infections and ways of combating the spread of the disease. The researcher noticed that there was no adequate attention focused on understanding the subjective experiences that AIDS orphans, and other children made vulnerable by HIV/AIDS, face throughout their lives. Most researches done on HIV/AIDS seem to be quantitative. This stems from their common quest to seek an objective understanding regarding the continuous increase of infections and ways of combating it (Akukwe, 1999; Barolsky, 2003 and Pharaoh, 2004). Some seem to focus on seeking the best cure for the virus and the preservation of life (UNAIDS, 2006). However, the other concern that some researchers raised relates to the question of what will happen to the children

whose parents died from AIDS (Dickerson, 2007; Landman, 2002 and Pharaoh, 2004).

Landman (2002) points that there is a lot that such orphans face. Consequently, they have to deal with too much too soon in their young lives. As HIV/AIDS is a dynamic pandemic, its impact on children, families and households unfolds gradually and in many directions. The challenge begins with a parent's HIV infection, and then through the more serious illnesses of AIDS and ultimately death. Children's lives are increasingly circumscribed by the economic problems that beset the family, by their lost or limited educational opportunities and by psychosocial distress and other difficulties that can lead to the worst outcomes (Levine, 2000 and Foster & Williamson, 2000). Such experiences have been found to have a profound impact on the child's psychological functioning and subsequent development, even well into adulthood (Landman, 2002).

The main focus of this study is to understand the experiences of AIDS orphans and other vulnerable children, as well as to establish whether those experiences had an influence on their identity development.

1.2 THE IMPACT OF HIV/AIDS ON AIDS ORPHANS

1.2.1 Loss and bereavement

Researchers such as Landman (2002) have highlighted that many AIDS orphans are going to face difficult challenges at a young age. They believe that as long as there are many adults who are infected with HIV and the high mortality rate which threatens the larger population of our country, there will be many children who are likely to lose one or both parents to HIV/AIDS. Like any other child who loses a parent, AIDS

orphans experience loss and grief. However, this (that is, their loss and grief) is said to be complicated and aggravated by the circumstances brought by HIV/AIDS (Siegal and Gorey, 1994; Booyesen, 2004 and Doka, 1989). The loss of a parent to HIV/AIDS is said to increase the emotional vulnerability of the children as the disease comes with a stigma attached. According to Dane and Levine (1994) this stigma is viewed as a powerful destruction that can disable individuals, families and communities to be open about their health or even the death of a loved one. The stigma seems to influence secrecy as families tend to hide the truth about the illness from extended families, friends, neighbours and community contacts. Some parents even go to an extent of withholding the truth from their children.

This can also cause isolation and reduce the level of support that the family might need in order to move forward. Children suffer the most from these effects because they are likely to be the ones left behind once the pandemic hits the home (Landman, 2002). Dane and Levine (1994) believe that these orphaned children are likely to carry lifelong emotional scars, as they might not get the level of support that they need to appropriately grieve and accept the death of their loved ones.

Freeman (2004) adds that careful consideration should be given to the mental status of such children, as they could be susceptible to mental illnesses emanating from unresolved grief and unsupportive environment. The children are generally subjected to living in fear and uncertainty, and the hope for a better life can slowly diminish. Payne, Horn & Relf (1999) further points out that there are already many adolescents who exhibit symptoms of depression related to their childhood and HIV/AIDS experiences, which puts them at an additional risk for emotional difficulties as adults. The loss of parents can make life difficult for such orphans because they could also become

vulnerable to extreme difficulties at a young age. In the end, such children are likely to face the possibility of dealing with a poor emotional and financial support structure. The impact of HIV/AIDS is that as parents die, families are dismantled (Booyesen, 2004, b). The result of this is that important things like roles and responsibilities are likely to be affected. For instance, surviving children might be forced to fend for themselves. Therefore, the issue of family structure and related aspects will be discussed to see how they contribute to the lives of AIDS orphans.

1.2.2 The structure of a nuclear family

As a result of parents dying from HIV/AIDS, older children are often forced to assume the role of parenting their younger siblings. The high infection rate and mortality rate in our country is predicted to force children to assume roles such as that of a provider as the main breadwinner will be gone (Department of Health, 2007). This high mortality rate and change in roles can lead to changes in the structure of the nuclear family (of parents and children) to the emergence of certain structures such as child-headed households, single-headed households and households headed by grandparents or extended families (Booyesen, 2004,b; Booyesen & Arntz, 2002 and Rees, 2004).

The death of parents or caregivers may result in child-headed households. There has been a rise in the number of single-headed families, with women being the majority in the field of single parenting (Gringlas & Weinraub, 1995). This compounds the problem because the proportion of women being infected and affected by the epidemic is a growing concern (UNAIDS, 2005). The Medical Research Council

(2005) also revealed that the mortality rate of young adult women has increased so much that there are more deaths of younger women than of women in old age. This implies that if the mortality rate is high among young women, and most of them are single parents, the children left behind are likely to be the hardest hit by this pandemic. Single-headed households are likely to suffer the most devastation, as there is already one parent and possibly one breadwinner for the entire household (Crew, 2003). In this context the death of a parent is further seen as a risk or catalyst for the development of child-headed households. Landman (2002) points out that child-headed households are also becoming a great concern as there might be limited support and mentoring for children in such households. Therefore, such families are at the risk of falling deep into poverty as well as the vicious cycle of HIV/AIDS. A few of these children are thought to be fortunate to be left with their grandparents who become their caregivers (Makiwane, 2004).

Madhavan (2004) observed that grandparents are now becoming “parents” to their grandchildren, following the death of their adult children. This circumstance has changed the structure of the nuclear family completely. The grandparents who are now becoming parents to their grandchildren face overwhelming responsibilities they might not be prepared for because they are in their old age. They are challenged by their insufficient financial state as they are likely to rely on pension fund. Their deteriorating state of health poses a threat to their ability to provide parental care that growing children need (Makiwane, 2004). Their situation is further complicated by the difficulty and pain of losing their own children and the thought of rearing grandchildren on their own. Children in such situations are said to experience deprivation in many areas of their lives. For instance, grandparents might find it

difficult to assist the children in many physical and psychological challenges that they might need support with.

1.2.3 Psychological well-being

Landman (2002) postulates that with the multiplicity of factors surrounding the loss of parents, it can be overwhelming and difficult for these children to comprehend everything they face at such a tender age. They might thus be susceptible to mental problems as they grow up. Even before their parents or any significant other dies, children living in families with HIV/AIDS-diagnosed individuals witness the pain and suffering that their loved ones go through every day (Dane & Levine, 1994). It becomes more difficult to cope with their situation because they might lack ongoing support from extended families and other social networks. Their situation can result in a sense of isolation and possibly a lack of parental love and care in their lives, which could have adverse effects on their emotional or psychological state.

These children experience many emotional hurdles that, for some, can result in the development of emotional or mental problems as they grow up. Booysen (2004,b) agrees that the psychological wellbeing of AIDS orphans is a growing concern because these children might need more than just clothes and a shelter in their lives. Their emotional state, following the trauma that they experienced, will thus require the necessary support. In their studies (Paige & Johnson, 2004) indicated some of the psychological disorders that might be caused or exacerbated by HIV/AIDS. These include depression, anxiety, post-traumatic stress disorder, school phobia and conduct disorder. It is also understandable that with increased chances of being emotionally and mentally overwhelmed by challenges imposed by HIV/AIDS at a young

age; these children's ability to progress educationally will be adversely affected.

1.2.4 Education

Pharaoh & Schonteich (2003) and Kelly (1999) refer to the impact that HIV/AIDS may have on the educational progress and opportunity of affected children. Studies show that if there is a family member with AIDS; especially the breadwinner, the average income falls by as much as 60%. In the face of reduced income and increased expenditure on health preservation, the money earmarked for school expenses is used for basic necessities, medication and health services (Booyesen & Arntz, 2002).

The opportunity to get education or progressing further with higher education is compromised by the fact that parents, guardians or breadwinners are no longer present, and economic devastation starts to take its toll (Bicego, Johnson & Rustein, 2003). The absence of parents and good support structure from extended families is likely to compromise educational opportunities for many children affected by HIV/AIDS.

In many households, education needs are likely to become the last issues in their list of worries because these families cannot afford the cost of fees and other school requirements. Even in situations where children are not withdrawn from school, education often begins to compete with many other duties that affected children have to do (Kelly, 1999). When caregivers or parents become ill and die, children who are unfortunate not to get support find that their responsibilities in the household increase dramatically. Some of these children might even have to change their roles in the family to that of a provider; and

this will eventually compromise the opportunity to get education (Pharaoh & Schonteich, 2003).

All the above mentioned factors and possibilities highlight the extent to which children and teenagers could be greatly affected by issues imposed by HIV/AIDS. Although the impact of HIV/AIDS is devastating for everyone, it is said to be more devastating for a growing child because children are often perceived as more vulnerable and disadvantaged than adults (UNAIDS, 2006). A growing child needs support and guidance through his or her life experiences to better his or her chances of becoming a productive member of society. Erikson (1968) points out that parental and societal influence play a vital role in the identity development of a child. He believes that challenges of our life experiences and the choices made, with or without the support of, or the influence of our significant other, greatly affect the direction of our identity formation. The following section elaborates on Erikson's understanding of identity development.

1.3 THE IMPACT OF HIV/AIDS ON IDENTITY DEVELOPMENT

According to Erikson (1968), identity refers to a person's stable, coherent and integrated sense of self. That is, who one is and what he/she stands for as a member of society. Most theories of identity development positively link family influences and parenting processes with development of identity (Mullis, Brailsford & Mullis, 2003). Healthy identity development seems to relate to the establishment of a healthy relationship between parents and their children which allows for individual freedom. The family can grant autonomy or feedback processes to either encourage or discourage individuality and innovation (Watson & Protinsky, 1998). Erikson implies that an environment comprising positive parental process as well as a

supportive environment has a high probability of encouraging a healthy identity. A healthy identity in this regard is a strong sense of how one perceives and defines him/herself.

The fact that Erikson's theory entails how parental or societal influences play a role on identity development makes it relevant to this study. This is especially so because the study explores the development of identity among children exposed to, and affected by, HIV/AIDS; as well as how their families and communities have been influential in their lives. It is important because it looks not only on the development of the child to adulthood, but also on how the family and community have an impact on that particular individual. Unlike many theories that generally discuss the primary principle of personality development, Erikson's elaborates further the development of identity under the stage of identity development versus role confusion. He refers to it as a stage at which an individual can be regarded as an adult because he or she can perceive and define himself/herself, and his/ her potentialities.

In the study conducted by Marcia (1993), it is indicated that the family is likely to be the most powerful of social systems that children and adolescents experience as they go through the process of identity formation. However, the challenge is that there are children who do not have proper families or who do not have families at all. Some don't have proper family bonds or attachments and just exist in narrowly constructed space comprising of fragile, damaged attachments. The bonds between them and those who are responsible for them are made even more tenuous by HIV infection and AIDS (Pivnick & Villegas, 2000). HIV/AIDS compromise the family's opportunity to be together and to share important things like affection, knowledge and support or encouragement (Madhavan, 2004). Many of these children might lack a

proper social context, as they are likely to be without the proper support of parents, extended families or neighbours. This could make them feel even more different and isolated from their communities.

The following key questions are pertinent: what happens to children coming from these broken homes that are likely to lack proper parental love, affection and guidance in their transformation from childhood to adulthood? How do they deal with the challenges resulting from, and relating to HIV/AIDS which are likely to manifest in their process of identity development? Do they experience role confusion or do they achieve a matured sense of self or identity that is expected in their environment? Have they discovered their inherent potential that is in line with how they perceive and define themselves as well as how others expect them to be? These conceptions and questions constitute the reasons for this study.

1.5 AIM OF THE STUDY

The aim of this study is to explore the multifaceted impact of HIV/AIDS on a child, including his or her identity formation. Firstly, the focus is to explore the challenges faced by children orphaned by AIDS or HIV-related illnesses as well as to give voice to the experiences and meaning gathered from it. Secondly, the exploration endeavours to understand the process of their identity development following the experiences they faced with HIV/AIDS.

This involves:

- the influence and contribution of their personal experience on their identity development. That is, the meaning and understanding they derived from their experiences.
- environmental (that is, family and community) influences and contribution to their identity formation.

This means that the impacts of HIV/AIDS on their psychological, economic, educational and psychosocial lives including identity development are the conceptual domains relevant to this study.

1.6 Objectives of the study

Given the aim of the study, the objectives of the current study are as follows:

- To explore the experiences of children orphaned by AIDS
- To determine whether their experiences have an influence on their identity development
- To ascertain how those experiences influence their identity development.

With the aim of broadening our understanding of the magnitude of the problem that South Africa faces and, most importantly, understanding the psychological impact of being orphaned by AIDS, the study also aims to contribute towards change by expanding knowledge and a deeper understanding of these individuals' experiences.

The next chapter deals with the literature review in conjunction with the theoretical framework of the study. Chapter 3 will focus on the research methodology, while chapter 4 will deal with interviews and findings. Discussion and Conclusion will be dealt with in chapter 5, which is the final chapter of this study.

CHAPTER 2: LITERATURE REVIEW

2.1 INTRODUCTION

Dickinson (2007) observes that everyday there are 1,600 children who die of HIV/AIDS, and so far there are 12 million children who have been orphaned by HIV/AIDS in the sub-Saharan Africa alone. Approximately 1 million African school children have lost their teachers to HIV/AIDS. In addition, up to 20% of the nurses in South Africa are HIV positive. In response to this observation, Dickinson (2007) poses the question: who will care for the children and who will be there to teach them?

In South Africa, HIV/AIDS is a worrying concern because of its incomprehensible impact on families, communities, the state of the country, and most particularly, its impact on children. A report by the National Department of Health (2007) states that the greatest challenge that children exposed to HIV/AIDS are likely to experience is orphanhood. As South Africa is one of the highly infected countries in the sub-Saharan region (UNAIDS, 2006), many children are at the risk of growing up without parents on account of the huge HIV/AIDS-infected adult population. In addition to worrying about who will take care of the children, there is a concern over the impact of HIV/AIDS on a growing child (Landman, 2002). Considering that children go through many stages towards the development of their identities, it has become interesting to see how AIDS-orphaned children have incorporated their experiences with issues of HIV/AIDS into the definition of their identity. This created a need to understand how one's experiences of HIV/AIDS could have an impact on one's identity formation. The literature review will discuss some of the challenges that AIDS orphans are likely to encounter. It will further refer to the theories that explain identity development in order to get an overall picture about identity formation.

2.2 DEFINITION OF CONCEPTS

The key concepts used in this study are defined below. This is to clarify their meaning as they are continuously referred to throughout the study.

Ballamay (2004) defines orphans and other vulnerable children as follows:

Maternal Orphans are children under the age of 18 years whose mothers have died.

Paternal Orphans are children under the age of 18 years whose fathers have died.

Double Orphans are children under the age of 18 years whose mothers and fathers have died.

Other Vulnerable Children are children who are vulnerable to other circumstances including HIV-related illnesses.

Orphans of AIDS OR HIV related illnesses are children whose parent or both parents have died due to AIDS or HIV-related illnesses.

Ego Identity or Identity, used interchangeably by Erikson, is defined as a person's stable, coherent and integrated sense of self; that is, how a person perceives and defines himself/herself (Erikson, 1968).

2.3 THE IMPACT OF HIV/AIDS ON ORPHANS AND OTHER VULNERABLE CHILDREN

2.3.1 Loss and Stigmatisation

HIV/AIDS is said to expose many children to loss and grief at a young age. The concept of loss involves more than just the death of a person. According to Payne, Horn & Relf (1999), loss can involve changes in

social roles and expectations, as well as changes in body image and functioning in one's environment. Bereavement refers to the loss of a significant person in one's life (Stroebe, 1993). Attig (2002) adds that bereavement is the state of deprivation, disruption or crisis in our lives, which we all experience following the loss of our loved ones. Stroebe (1993) stresses that bereavement is unusual insofar as it takes us out of the normal patterns of our daily lives and disrupts the smooth unfolding of our life stories. Children's lives are greatly affected and disrupted as HIV and AIDS continue to claim most of the adult population in South Africa (UNAIDS, 2006). Their normal pattern of life is likely to be disrupted by the challenges imposed on their lives once their parent(s) become sick and eventually die from AIDS. Pivnick and Villegas (2000) add that some of these AIDS orphans are likely to witness their parents' prolonged suffering and death. This process can be difficult for them to endure.

In this context, some AIDS orphans are likely to experience anticipatory grief. During the process, the family and children are torn between hoping for recovery and anticipating the passing of their loved ones (Doka, 1989). Pivnick and Villegas (2000) believe that this process can be extremely difficult for children because they see their loved one slipping away from them. It becomes more difficult to cope with the loss when more family members die from HIV/AIDS. Some AIDS orphans are likely to experience multiple losses. Sherr (1995) defines it as a situation whereby more than one family member dies in a short space of time. Due to the fact that a large proportion of the population in South Africa is believed to be HIV positive, UNAIDS (2006) predicted that many people are going to die in a short period of time. The fact that HIV/AIDS is a stigmatised disease can make the loss for AIDS orphans even more difficult.

Siegal and Gorey (1994) stress that HIV/AIDS has become a universal disease and its social stigma remains a serious burden for HIV-positive individuals and their families. The loss can thus be difficult to cope with because of the fear that is associated with HIV/AIDS. The stigma associated with AIDS frequently causes families to hide the truth about the illness from extended families, friends, neighbours, communities and even their children (Dane & Levine, 1994).

Like any other child who loses a parent, these orphans experience grief; however, their pain seems to be exacerbated by prejudice and social exclusion. According to Siegal and Gorey (1994), the powerful stigma attached makes children not to talk about the illness and death of their loved ones. This denies them the opportunity to address their loss in the relevant context. If parents find it difficult to talk about their illness to their family and children, children also find it difficult to talk about their parent's death. The secrecy and lack of openness about the disease pushes more and more people to their hiding places and perpetuate the stigma (Dane & Levine, 1994). The stigma is likely to heighten the instance of "persistent and unresolved grief" (Parkes & Weis, 1983). Children and teenagers might be unable to move past the feelings associated with their loss, such as guilt or anger, as these feelings would not have been addressed and resolved properly. They are most likely to cause them to carry life-long emotional scars as they have been robbed of the opportunity to appropriately grieve (Dane & Levine, 1994).

The impact of HIV/AIDS makes the loss for AIDS orphans unique, because it places them in a realm of paradox. This is a situation that says, "grieve, but you are not allowed to grieve freely and openly because we, the extended family and/or community, might reject or isolate you. One is expected to grieve openly and freely by sharing

their feelings and thoughts about their loss, while on the other hand, the power of stigmatisation and the resultant rejection and isolation implicitly discourage one to talk freely and openly about their loss. Doka (1989) also explains this as disenfranchised grief. Even though many people are believed to be infected with the HIV disease and many others are already dying, it appears that individuals, families and communities still find it difficult to talk about it in order to support each other and fight the disease instead of each other. The impact of HIV/AIDS is not only at an individual level, but families and communities are greatly affected.

2.3.2 The Structure of the Nuclear Family

An important aspect of the distress felt by orphans following the loss of their parent(s) is a disruption in the pattern of mentoring, care and support given by the household head, usually the mother or the father, because the highly infected population in South Africa is aged around the adult-parent population (UNAIDS, 2006). A study conducted by Bicego, Johnson & Rustein (2003) shows that not only parental care and support will be disrupted but that household roles may be affected and reordered after the catastrophe of parental deaths. As the mortality curve of the pandemic peaks, many people in the adult-parent population will die, and this means that many children are likely to lose one or both parents to HIV/AIDS, and affect the structure of the family and roles of the family members (Booyesen & Arntz, 2002). The household structures that are expected to emerge as a result of deaths are female-headed households, grandparent-headed households and child-headed households (Bicego, Johnson & Rustein, 2003 and Pharoah & Schonteich, 2003).

In South Africa most of such households already live below the poverty line, and are therefore vulnerable and susceptible to extreme poverty and underdevelopment (Booyesen, 2004,b). Sishana (2004), Cross, (2001) and Simbayi, (2001) agree that HIV prevalence seems to be higher among households of lower socio-economic status. In their discussion, they indicate empirical evidence on the link between poverty and HIV/AIDS. Members in households that are struggling to survive economically are likely to be exposed to unpleasant circumstances such as abuse, exploitation and HIV infection as they try to survive economic hardship. Households in lower socio economic status, with member(s) who are HIV-positive are likely to feel the impact when their loved ones begin to be in a great need for health care services and medication. As members of the household become ill, and are forced to give up their jobs, household income is likely to fall drastically (Booyesen, 2004, a). Poor households have to cope with the changes in income and the need to spend money on health care, education, food and sanitation which might lock them further into spirals of poverty (Crew, 2003). Although HIV/AIDS affects many families, single-headed families might face more challenges as the only adult members of the household become ill and are forced to give up their jobs (Booyesen, 2004,b). This places the surviving family members under severe pressure to make ends meet.

2.3.2.1 Female- and/or Single-headed Households

In her study, Cross (2001) observes that more and more households are now under the authority of women and are also supported by women's earning power or, alternatively, by women's pension income. However, the economic demographics of the HIV/AIDS crises underline the likelihood that women are carrying most of the load as the burden of coping with children is likely to be closely gendered in South Africa

(Marcenko & Samost, 1999). Monasch and Boerma (2004) also make the point that in Southern Africa one in three households is headed by a woman. They argue that this is because women are most likely to take the responsibility for their children and their grandchildren, and that grandmothers are also most likely to care for their grandchildren.

According to the Department of Health (2007), women are disproportionately affected by HIV/AIDS, and account for about 55% of HIV-positive people in our country. UNAIDS (2006) also reported that the proportion of women being infected and affected by the epidemic is high. Although women are infected and affected more than other populations, their infection rate has indicated a decline, showing that learning and change with regard to protection and prevention from HIV/AIDS is taking place (Department of Health, 2007). Women in the age group of 25-39 years are regarded as the worst affected, with prevalence rates of up to 40% (Department of Health, 2007). This can be a problem because if most of this 40% in this age group are single parents, many households will soon require assistance. Most in this age group include not only the most productive members of society, but also those who are responsible for caring for both the young and the elderly. The high rate of mortality among women at ages of their prime economic activity exposes the already vulnerable households to further shock, and locks the households into spirals of underdevelopment (Sishana, 2004; Booysen & Arntz, 2002 and Booysen, 2004,b).

Such families are also likely to fall deep into poverty and to be exposed to other vulnerable situations (Crew, 2003). Given that it is difficult for a single parent to provide financial and emotional support for his/her children, such children are disadvantaged even more when the only parent suffers from a chronic illness. Not only are they more vulnerable

to extreme poverty, but they may also lack the necessary support from extended families and neighbours, when they are compelled to care for their sick parent. Such children are also susceptible to different kinds of abuse and exploitation because of the parent's inability to give them appropriate care and guidance (Landman, 2002).

A study conducted by Bicego, Johnson & Rustein (2003) suggests that the loss of both parents places the child at a particular disadvantage. However, the loss of a mother appears more detrimental than that of a father. Foster and Williamson (2000) observe that maternal orphanhood has proved to be more distressing than paternal orphanhood. The widespread absence of fathers and the lack of support on the part of men for families and children in South Africa is a major gap in the potential resources for affected children (Pharaoh, 2004). Statistics South Africa (2005) has estimated that close to half of all children under the age of seven years live only with their mother and fewer than half of all maternal orphans in South Africa live with their fathers.

In South Africa the more deep-rooted institutional problems of poverty, underdevelopment and low status of women in society have been associated with the high prevalence of infection among women, and poor support from men (Pharaoh, 2004). In the end, the children are likely to suffer the most. With the death of the single parent and the only breadwinner, child-headed households are likely to manifest in numbers.

2.3.2.2 Child-headed Households

HIV/AIDS has led to the emergence of a relatively new sociological phenomenon, the child-headed household (Kelly, 1999). With all the

adult members of the family dead, children are left to fend for themselves. Generally, the oldest child assumes economic and parental responsibility for the others. A study conducted by the Human Science Research Council (2005) shows that young women are twice more likely to head a household than men. As roles are more gendered in South Africa, women are likely to assume the nurturing role of taking care of children (Makiwane, 2004).

Children are forced to assume roles that they are not ready to take. For girls and young women acting as caregivers, this constitutes a shift from being dependant upon their parents to becoming responsible for providing for the family. The quest for stability and security can result in potentially exploitative sexual relationships with older men, unwanted pregnancies, single motherhood, and a continuation of the spiral of poverty as well as the risk of HIV infection (Webb, 2005). In contrast, young boys in despair would join the growing ranks of street children who soon become professional beggars, glue sniffers, drunks and criminals and even exposure to sexual abuse (Landman, 2002). The impact of the epidemic on the quality of life is seen by the increase of work performed by such children.

The dynamics surrounding orphanhood may also leave children emotionally and psychologically vulnerable. These orphaned children are at the risk of growing up without adequate parental support and love, but become preoccupied with the need to survive and cope in their situation.

Child-headed households are likely not to receive proper support from extended families and communities due to the stigma associated with HIV/ AIDS. The shame, fear and rejection that often surround people affected by HIV/AIDS can create additional stress, isolation and

prejudice for children (Pharaoh and Schonteich, 2003). Some children are lucky to be taken in by their extended families such as their grandparents.

2.3.2.3 Grandparents as Emerging Caregivers

A grandparent's idealistic picture of a quiet old age is now being shattered by the AIDS pandemic. Makiwane (2004) noticed that the elderly, who are now caring for the sick and dying members of their family, and rearing their orphaned and vulnerable grandchildren, emerge in a complete reversal of roles. The grandparents face the problem of adjusting to the extension of their own family and the proper raising of children again. They are often unprepared for this emotionally, financially and physically challenging task.

Rajcoomar and Roper (2006) point out that some of the problems that grandparents face are chronic poverty, diminished physical and emotional health, lack of support from extended families and communities, schooling of the children, health of the children, community reaction, stigma and discrimination. However, grandparents have also been noted to confabulate about the death of their offspring to protect the family's dignity. This degree of secrecy leads to social isolation of grandparents who are now in great need of support (Paige & Johnson, 2004).

In their study, Booyesen and Arntz (2002) observe that children cared for by grandparents are likely to face a 'second orphanhood' when their grandparents die. They are thus exposed to double the pain, abandonment and extreme poverty. Such circumstances bring about complicated emotional hurdles for AIDS orphans and expose them to even greater struggle of surviving and growing up on their own. With

the loss of their grandparents, such children are likely to face double orphanhood. The difficulty that started in their childhood is seen continuing to affect them as they grow into their adulthood. Through their life experiences we get to understand how HIV/AIDS can be intrusive, and that it also challenges the psychological well being of individuals affected.

2.3.3 Impact of HIV/AIDS on Psychological Wellbeing

Siegal and Gorey (1994) suggest conditions that can influence adjustment to parental death and mental health to be (i) the quality of care and support children receive from their primary caretakers after death, (ii) open family communication about the illness and death, and (iii) the stability of their environment. After the death of a parent, children need love, support and care. The quality of care and support children receive after a parent's death can protect them against psychological disorders later in their adult life. When their attention is not focused on who will provide their next meal, or how will their school needs be met, grieving might not be inhibited.

Bereaved children also need an environment in which they can feel free to communicate their thoughts and fantasies about their parent's death (Siegal & Gorey, 1994). Open communication about parent's death can help alleviate fears and uncertainties about the future as caretakers can be able to address them. Children's adjustment to parental death and mental health has been found to be less difficult when families tolerated the open expression of anger, guilt, sadness and loss and share the information and feelings about the loss (Payne, 2004). Parkes and Weis (1983) also believe that when children are inhibited from asking questions about a parent's illness and/or death, misconceptions can persist and can be a significant source of

psychological distress. Feelings such as powerlessness and helplessness can ensue if they are not addressed.

Worden (1991) believe that bereaved children can feel more secure in, and draw comfort from, familiar surroundings and predictable routines. Furman (1974) and Rutter (1979) elucidate that changes in children's environment at the time of parental death are stresses that could jeopardize the children's adjustment and their mental health. Adverse environmental change can contribute negatively to children's perception of having little control over their world (Siegal & Goery, 1994). Therefore, consistency and environmental stability can contribute positively to effective adjustment and mental health after a parent's death.

Freeman (2004) points out that children living in families with HIV-infected and/or AIDS- diagnosed parents are most likely to be at the risk of psychological distress resulting from the traumatic experience that comes with HIV/AIDS. Their world starts to change when their parent's health starts to deteriorate, and eventually going through the trauma of witnessing their parent's death. Telingator (2004) adds that children who experience the death of a parent are at a higher risk of ongoing psychological turmoil if they lack ongoing support from caretakers and other social networks, than those children who are fortunate enough to have consistency and predictability in their lives before, during and after a chronic terminal illness strikes a member of their family. The level of uncertainty and the lack of stability that comes with the situation can make them feel uncertain about their lives or future, which can be emotionally overwhelming and discouraging.

As HIV/AIDS goes hand in hand with isolation and discrimination, this might result in a situation where care and support might be very limited for some of the AIDS orphans (Freeman, 2004). The lack of support can thus make AIDS orphans feel abandoned and isolated. It is mainly because in their situation the death of a parent can be equated with a lack of emotional and material support to see them through. The lack of support that appears to be influenced by fear of stigmatisation means that they can forfeit important things like love, care and support to help them through their ordeal. Paige and Johnson (2004) observe that these children often experience anger resulting from feelings of abandonment by their parents and the lack of support from their extended families.

Some researchers have highlighted some of the physical changes that can be influenced by the impact of HIV/AIDS. Pivnick and Villegas (2000) believe that children exposed to their parent's bouts with life threatening illness, and thereby witnessing their parent's death, report periods of heightened uncertainty, vulnerability and difficulties associated with sleeping and eating. Aronson (1995) further states that children and adolescents exposed to HIV/AIDS show symptoms of low tolerance for frustration, acts of rage, fighting in school, class clowning, and truancy. Other researchers discovered some of the disorders caused or exacerbated by HIV/AIDS to be depression, anxiety, post-traumatic stress disorder, school phobia and conduct disorder (Paige & Johnson, 2004; Siegal and Gorey, 1994 and Marcenko & Samost, 1999). Caplan and Douglas (1969) add that despite their effort to appear normal, such children were found to have higher rates of depressed mood, phobias and school-related problems. Their situation can impose emotional challenges that they might not be ready to deal with and resolve successfully.

The researchers mentioned have indicated that the impact of HIV/AIDS on children can be detrimental to their psychological wellbeing. There are researchers who also believe that HIV/AIDS impact can be a risk to the educational progress and opportunity of children affected by this pandemic. The following section shows how the impact of HIV/AIDS poses a risk to the education of some of the children affected by HIV/AIDS.

2.3.4 The impact of HIV/AIDS on education

One of the factors associated with the impact of HIV/AIDS on households is a severe drop of average income for the entire household because of death of breadwinners (Sishana, 2004). This consequent circumstance has been highly correlated with the drop in educational provision and progress for many children affected by the impact of HIV/AIDS (Pharaoh, 2004). It becomes difficult to continue with school when there is little or no support from others, and when school needs start to compete with other more important needs in the household.

Bicego et al. (2003) observes that the onset of illnesses followed by deterioration of parent's health marks the beginning of the deterioration of the family unit, and trauma in the psychological and material life of children, including education. Education is firstly disrupted when parents or a guardian become progressively sick and requires care from the family, usually the children. Foster and Williamson (2000) add that due to limited financial status and inability to afford care facilities for the sick parent(s) the children are likely to assume care giving duties to their ailing parent(s). It is in this respect that older children are usually the ones who have to take over household and care giving chores. It can be difficult for them to

continue with school when there is no one to take care of their ailing parent(s) therefore school often takes the last position in their lives. In certain situations when the parents become ill and are unable to get income, some of these children are sometimes forced to find some source of income for food and other basic necessities in order to survive (Rau, 2002). In their endeavour to provide for their families, some of these children can be exposed to all sorts of abuse and fall into the vicious cycle of HIV. Some are swallowed into the role of being the provider; so it becomes difficult for them to continue with school. This is often the position as their siblings might be dependant on them after the death of their parents.

Kelly (1999) states that HIV/AIDS makes it difficult for many children to enrol in or complete school, attend on a regular basis, or perform as they should in school. He observes that as the majority of infected children may not be aware of their HIV status, they may begin to experience extensive school-related problems when the symptoms of AIDS start appearing. In addition to their suffering and trauma, their condition will often occasion fear, anxiety and uneasiness in their schoolmates and teachers (Kelly, 1999). They may experience stigma, discrimination and social ostracism. The recurring bouts of illnesses can interrupt their attendance and diminish their learning opportunity. Eventually they may stop attending school (Richter, 2004).

There are those children who get infected as a result of exploitation and sexual abuse. South Africa has one of the highest rates of violence against women and children (Kelly, 1999). It is during such instances of violence that both rape and sexual abuse are increasingly committed rapidly, and cause grave concern for women and girl children. As a result, girls become vulnerable to sexual exploitation, rape and abuse, and eventually get infected with HIV. Some of these girls can find it

difficult to continue with school because of constant HIV- related illnesses that often disrupt their school attendance and progress. The stigma that is also associated with HIV/AIDS also contributes to lower school attendance because some of the children might not want to feel isolated and discriminated against at school.

Some poor households are impoverished even further by the impact of HIV/AIDS with the result that the children's capacity to learn is also imperilled by a combination of poor nutrition, hunger, trauma and emotional distress (Pharaoh, 2004). Conditions such as these are likely to impair their thinking, ability to concentrate, attend to environmental stimuli and performance in school tests.

AIDS also undermines the capacity of the educational system to serve its learners. The capacity of many schools and educational systems have been devastated by the sickness, absenteeism, declining morale and an increasing number of deaths among teachers and other educational personnel (Kelly, 2004). Department of health (2007) also concurs that the quality and quantity of educational provision is compromised by HIV/AIDS impact.

Children need hope and continuity. It is education, through school, that can offer that hope for many of these AIDS orphans. Donahue (2005) stress that orphaned children, in particular, need schooling, because school is characterised by normality, routine and stability. These are the factors that can help an orphan child cope with disturbing and bewildering events in their lives. Kelly (1999) ascertains that school attendance is one of the great antidotes to their sense of insecurity and worry over their home circumstances. It can help the child to develop a renewed sense of efficacy in relation to life, restore some lost confidence and offer hope that life can move forward.

The lives of most of these AIDS orphans are likely to be disrupted by many challenges that have been discussed in this section or chapter. It is therefore important for this study to get an understanding of how these challenges can impact on the orphaned children's identity development. The following section discusses the theories of identity development and the impact of HIV/AIDS on identity development.

2.4 THEORIES ON IDENTITY DEVELOPMENT

Different authors give different views about identity development. Meyer (1989) propose that every personality theory is based on certain assumptions about the nature of the person and the environment he/she dwells in. The authors state that a personality theory usually includes a complete developmental theory which explains (i) how the structural and dynamic aspects of the person develops, (ii) how the child's behaviour gradually changes until he/she reaches adulthood and (iii) the interplay of other important factors such as his/her environment, family and community. Many theorists indicate the impact and influences of one's environment as well as the individual's inner need to develop and grow to be who he/she inherently has to be as contributing significantly on identity development. The theories of Carl Rogers, Freud and Erikson will be discussed to further understand the development of this identity.

Freud suggests that there are often two dominant forces that are likely to be at play when it comes to personality development. These are individual drives and environmental demands or expectations. The individual forces often represent genetic drives such as biological (emotional and sexual) drives, while environmental forces usually represent external demands and expectations from one's social environment. According to Freud, the individual is usually in a constant

conflict between his/her drives or needs and moral societal expectations or demands. He believes that this is the process whereby the child learns and develops by coping with the conflict presented by the person's inner drives and societal expectations from one stage to the other (Meyer, 1989).

Freud describes the development of the individual as a succession from one stage to the other. He describes six stages of personality development, which are characterised by different sexual drives that have to be met without conflicting with societal norms or expectations (Meyer, 1989). Progression and development from one stage to the next is seen as a result of a change in the drive, as well as the management of the conflict presented by the two different forces (inner, genetic predisposition and societal expectation or demands). The final stage, termed genital stage, emerges at adolescence and is regarded as the pinnacle of development and maturity. At this stage, Freud highlights, there is a complete physical maturation of the individual, as well as the ability to minimize the conflict that might arise due to the need to fulfil one's drives and be socially appropriate (Maddi, 1996). It is at this stage that the individual is seen as matured because he/she is able to satisfy his/her needs in a socially approved way (Engler, 1989).

Freud also ascribes the importance of the role of the social environment. He explains that the social environment can be represented by a child's parents. The parent's conduct has a profound influence on how well and in what ways the child will cope with the problems presented by each stage, and largely determines how successful the child will progress to the next stage (Meyer, 1989). The child has inner needs that he/she would like to fulfil; but there are also parental expectations or societal expectations and demands that

he/she has to consider. He/she has to address both with as minimal conflict as possible. Freud asserts that the endeavour to fulfil one's drives and at the same time minimising conflict with societal norms or expectation as much as possible in each stage is the actual moulding process of an individual's personality (Maddi, 1996).

Once the individual is able to gratify his/her inner drive and minimize conflict with his/her environment, he/she is able to move to the next stage of development because he is regarded as matured. He suggests that the moulding process of our identity as adults is determined by our maturation and influences exerted by the social environment as well as the ability to deal with the conflicts that accompany each stage (Engler, 1989).

Freud's theory of personality development generally touches on important aspects that play a role in one's personality development and eventually influences identity development. As one learns to cope with one's drives and societal norms it influences how the rest of one's life will be. Freud's ideas of personality being influenced by environmental forces as well as drives or needs of the individual are similar to the ideas of Carl Rogers as in the Self Concept theory.

In terms of this theory (self concept), Carl Rogers believes that the core tendency of humans is to actualise their inherent potentialities; and the environment is there to play a facilitating or inhibiting role in the process of personality development (Moore, 1989). He believes that each individual has the actualizing tendency, which is the organism's push to become what its inherent potentialities make it to be. These potentialities are aimed to maintain and enhance life (Maddi, 1996). Rogers believes that these inherent potentialities are genetically determined because every organism genetically strives towards growth and development of its inherent nature, which is a

factor that cannot be paused or stopped (Moore, 1989). He also notes that although the tendency to actualise one's inherent potentialities follows genetic determinants, they are also subject to environmental influences.

Rogers suggests that environmental influences such as societal evaluations and opinions can either impede or facilitate the actualisation of one's inherent potentialities. He suggests that unconditional positive regard from significant others play a vital role in how the self concept develops. According to Rogers, a young child has two basic needs. These are the need for unconditional positive regard by others, and the need for positive self regard (Engler, 1989). Unconditional positive regard refers to being loved and accepted for who one is. Maddi (1996) defines unconditional positive regard as significant people valuing and respecting you as a person, and therefore supporting and accepting your behaviour or situation even if they disagree with it. Moore (1989) asserts this to be the human being's basic need for approval, appreciation, love, admiration and respect. To fill this need, a child can adopt the wishes and values of others to earn esteem. Positive self regard follows automatically if a child has received unconditional positive regard. The child is seen as requiring that esteem from others in order to feel positive about him or herself.

Carl Rogers believes that out of that interaction of the individual and his/her environment emerges the self or the concept of who one is (Engler, 1989). According to Rogers self-concept is how the person perceives himself or herself. The self concept depends in a large measure on the kinds of regards the individual receives from others. Carl Rogers's point is that valuation of others plays a significant role in the development of the self structure (Engler, 1989; Maddi, 1989). He

adds to this idea by introducing what he calls conditional positive regard, whereby only some, but not all, of an individuals' actions, thoughts, and feelings are approved of and supported by significant others. This becomes a situation whereby a person will sometimes experience non- acceptance by significant others and that he will feel worthy only when he has fulfilled certain conditions laid down by them. Rogers refers to this as conditions of worth, or the standards created by societies for discerning what is not valuable about them (societies). Rogers regards as the society's failure to the human being. Thus, as an individual develops a self-concept he/she incorporates within those values or standards.

According to Carl Rogers, the congruent or well-adjusted person sees himself or herself as he/she really is, and has a self-concept that actually corresponds with his/her actual potential (Moore, 1989). However, the more conditional positive regards the individual receives, the more he/she includes conditions of worth in his/her self concept and the more incongruent he can become. In other words, there is lack of congruence or fit between his self concept (how he/she perceives himself or herself) and his/her true inherent potentialities (Moore, 1989).

Both Freud and Rogers' theories address important aspects that often play a vital role in the development of one's identity or self-concept. These constitute the inner/inherent need for the individual's growth and survival, as well as influences exerted by the environment he/she dwells in. Both theorists stress the notion that it is the nature of a human being to strive to fulfil his/her needs, but also paying attention to societal expectations and regards for enhancement and actualisation of the self or development of its true identity. The generalised way in which they talk about the development of

personality and identity tends to limit their discussion about the complex processes of identity development during the stage from adolescence to adulthood. Erik Erikson's theory of Ego Psychology has been adopted for this study as it seems to have more light and relevance on identity development. This theory has been adopted in this regard because the process of ego identity which is dominant during the stage of adolescence to adulthood has been discussed in more detail.

Rogers proposed general principles of development rather than formulating specific stages and this gives a vague picture of when do the identity processes begins or heightens in an individual's life. Whereas Freud suggests that personality development is determined by certain biological and intrapsychic forces and processes during the first five or six years of life, personality development is complete at about six years of age (Meyer, 1989). According to Meyer (1989) Freud concentrated on the first three stages of development which covers six years of life because he maintains that the individual's personality characteristics are permanently fixed during those periods. In contrast, Erikson believes that individual's development consists of the progressive and lifelong evolution of the individual's inner potentials (Meyer, 1989). His suggestion that development of personality continues throughout life translate that identity is being moulded through each of the stages and heightens during the stage of identity versus role confusion. He further assert that development is also automatic as its particular details is determined by the specific challenges and possibilities which the social environment makes available to the individual, while the success of development depends on the nature and quality of the individual's interpersonal relationships (Maddi, 1996). He says personality is moulded according to the specific challenges and possibilities made available by the social environment

as well as the kind of relationships one has with his/her family and community.

Erikson's perspective is particularly relevant for the study because HIV/AIDS is viewed as a psychosocial issue that also has a progressive influence on the lives of many orphaned children from childhood to adolescence and right into their adult years. As AIDS orphans identity or personality development progresses throughout their lives, HIV/AIDS impact also progressively influence their lives from childhood to adulthood. It is therefore the interest of this study to explore how their lives and identity has been progressively affected and eventually moulded into the individuals they are. His theoretical framework also takes into consideration the kind of challenges that HIV/AIDS orphaned children endure as well as the kind of social environment and interpersonal relationships they were subjected to throughout development of their identity.

The nature of Erikson's theory also resonates with the study because his position and direction on personality development emphasises a more psychosocial nature than biological forces (Maddi, 1996). This is seen throughout his stages of development that reflect a more psychosocial nature. For instance, trust versus mistrust or autonomy versus doubt. Unlike that of Freud that have more of a biological reference, for example, oral, anal or phallic stages. This is particularly important because in this study HIV/AIDS is viewed as a psychosocial issue that affects many orphaned children. Therefore the study intends to explore the psychosocial aspect or nature of HIV/AIDS and its impact on orphaned children's identity development and not necessarily its biological influence.

2.5 ERIKSON'S PSYCHOSOCIAL THEORY on IDENTITY DEVELOPMENT

2.5.1 The Structure of Personality according to Erikson

Meyer (1989) describes Erikson's view of the structure of personality as including a kind of executive agent, the ego, and two other agents or protagonists called the id and the superego. Erikson (1959; 1968) shared some similar ideas about the structure of personality with Freud as seen in his description of the id and superego. Although he does not draw much attention to the id and superego, he describes the id as the drive element, a force responsible for indicating the physical, sexual, emotional or social needs of the individual. He says drives are forces which energise an instinctive pattern within the human being. It is regarded as the mental representation of the individual's bodily needs because it indicates what the individual needs. The superego, also referred to as the moral element, is regarded as a representative of society's moral codes, and has the function to make the individual aware of those codes (Meyer, 1989).

Erikson focuses mainly on the ego, which he describes as that aspect of personality which makes possible co-ordinated and planned functioning (Meyer, 1989). Erikson's description of the ego is that it has an overall unifying purpose, an executive agent that mediates between the id (individual's needs or drive) and superego (society's moral demands or expectations) in order to find solutions that maintain harmony and yet encourage development. According to Erikson, the ego develops throughout life and reaches its climax during adolescence when the individual is ready to establish his or her identity (Engler, 1989). Erikson's view of ego development is discussed in the next section of personality development.

2.5.2 Personality Development according to Erikson

The basic principle of ego development according to Erikson is that the process of personality development is the result of two simultaneous and complex influences; namely (i) genetic, that is, inherent or internal influences, and (ii) social influences, that is, external influences (Meyer, 1989). Erikson (1968) believes that these two forces work differently and in a complex manner to achieve one purpose; that is, to accentuate an individual's personality trait. Development comprises the manifestation of characteristics according to a genetically determined ground plan.

According to this genetically determined principle, the individual's characteristics emerge at certain ages and in a particular sequence, albeit in such a way that the person constantly develops as a whole (Erikson, 1959). The principle implies that development of the individual's characteristics takes place in both visible and unnoticeable manner. For instance, in physical development, a baby's teeth start growing long before birth, although they become visible only when they cut through the gums at about eight months. Erikson believes that this process is similar to personality development. For instance, personality aspects such as cognitive abilities and social skills still develop even when there is no overt evidence of their development. This means that each personality characteristic continually develops even though the development may not be evident at a specific age. While one specific trait dominates the development scene at any particular age, changes occur simultaneously in all other areas of the individual's personality. Erikson describes development as a progressive process and that certain traits of development keeps on

developing even when they are not visible to the eye and even when other traits are dominating development.

Erikson suggests that although development occurs throughout one's lifetime, there are stages at which a certain personality characteristic is heightened for development. In his view, the fact that these personality characteristics become heightened at specific stages of an individual's lifetime development is what he referred to as a genetically ground plan (Maddi, 1996). In his discussion, Erikson also mentions another factor influencing development; namely, societal or environmental influences.

Erikson (1959) adds that society exerts an influence in that it makes certain demands on the individual and, at the same time, offers certain opportunities for growth. These demands and opportunities are in accordance with, and complementary to, the developmental potential and needs of the individual at each stage of development. For example, society expects a six-year-old child to start acquiring certain skills, and simultaneously gives him/her the opportunity to do so through schooling. At the same time, society can present contexts or situations which can be conflicting and challenging to the individual. Societies are obviously made of different perceptions and dimensions which have tendencies to influence how individuals think and perceive things.

According to Meyer (1989), the development of the ego is clearly outlined in Erikson's psychosocial stages ranging from birth to old age. Each developmental stage is characterised by what Erikson calls a developmental crisis arising from the interaction between genetic development and social influences. The needs, possibilities, expectations and opportunities which emerge in each stage invariably

demand a choice between two opposing developmental possibilities. Erikson calls this choice a developmental crisis.

Engler (1989) adds that Erikson's psychosocial stages centre on an emotional polarity or conflict that children encounter at certain critical periods. New environmental demands interject positive and negative emotional components into the development of personality. If the conflict is resolved satisfactorily, the positive components are reflected to a higher degree, but if the conflict persists or is not adequately resolved, the negative components predominate. Erikson further states that it is at that moment that family/parental processes and societal influences play a role on how we eventually solve the crises and incorporate that into how we perceive and define ourselves (Engler, 1989). This is especially important for the study because it would be interesting to see how an individual's experiencing the impact of HIV/AIDS, deals with or without parental influences and the impact of societal perceptions as well as how they incorporate those experiences into how they perceive and define themselves. Engler (1989) indicates Erikson's psychosocial stages in the table below.

2.5.3 Table 1. Stages of identity development according to Erikson

Ages	Psychosocial Stages	Ego Strength
Infancy	Trust vs. Mistrust	Hope
Early Childhood	Autonomy vs. Doubt	Will Power
Play Age	Initiative vs. Guilt	Purpose
School Age	Industry vs. Inferiority	Competence
Adolescence	Ego identity vs. Role Confusion	Trustworthiness
Early Adulthood	Intimacy vs. Isolation	Love
Adulthood	Generativity vs. Stagnation	Care
Maturity	Ego Integrity vs. Despair	Wisdom

The adolescent phase is where identity or ego development is heightened. The focus of this study is going to be on this phase. That is, the stage of Adolescence: Ego Identity versus Role Confusion: Trustworthiness or Reliability. Ego or identity development is said to reach its climax during adolescence when the child is ready to establish his or her identity (Engler, 1989). This process of ego identity development requires that one compares how he/she perceives himself or herself, as well as in accordance with how significant others appear to expect him or her to be. According to Erikson's theory of ego or identity development, adolescents are expected to answer the

question, “who am I?” satisfactorily. If they fail to do so, they will suffer role confusion (Engler, 1989). It is important for adolescents because they are on a quest for self image, continuity in life and congruence between the self image and the expectations of society. The individual is said to have a sense of identity when he/she manages to integrate all his/her earlier identifications, drives, wishes and expectations, abilities and skills, with the opportunity his/her society offers him/her (Maddi, 1996 and Erikson, 1959, 1968). It also denotes certain gains that an individual must have derived from his or her experiences throughout childhood and adolescence in order to be ready for adulthood.

Erikson maintains that ego identity rests on societal influences and genetic predisposition. He, therefore, believes that it is important that social organisations permit a child’s capacities and potentials to develop (Engler, 1989). Most research studies indicate that there is a high correlation between contributions of family relationships and positive ego identity development (Cooper, Grotevant & Condon, 1983). The following section sheds light on how societal or environmental influences such as those exerted by the impact of HIV/AIDS are likely to influence an individual’s identity development.

2.6 HIV/AIDS AND IDENTITY DEVELOPMENT

The literature so far indicates that there is a theoretical and empirical consensus that suggests that the family context has an important influence on the adolescent’s ability to successfully negotiate important developmental tasks such as ego identity development. This is because the effective quality of family relations or the emotional closeness existing between family members is associated with high levels of self-esteem or psychosocial competence that can help the

adolescent (Papini, Sebby & Clark, 1989). Schultheis and Blustein (1994) highlight an important aspect in their findings that a close relationship between adolescents and their parents is inversely associated with the diffusion status. This suggests that such relationship may provide the sort of emotional support that fosters commitment to an identity. Strong bonds can offer the adolescent a sense of direction and advice during his/her quest for identity (Matheis & Adams, 2004).

There seems to be a consensus with regard to a relationship between separation-individuation and identity development as different researchers give their account of how they see this relationship. Separation-individuation has been defined as a developmental phase during which the adolescent becomes less dependent on the family and takes increasing responsibility for his/her own behaviour and identity (Blos, 1979). Separation-individuation is explained further as the individual's emotional disengagement from parents and the ability to gain a sense of identity as a separate individual (Grootevant & Cooper, 1998).

Sullivan and Sullivan (1980) describe this as the goal of adolescence, which involves the almost paradoxical task of increasing one's independence from parents while maintaining affection and commitment with them. Cooper, Grotevant & Condon (1983) agree that a moderate degree of emotional closeness or attachment in conjunction with adolescent separation from the family of origin may foster identity achievement and commitment. However, that task of developing an adolescent's individuality while trying to maintain relationship can also lead to conflict and role confusion.

Campbell, Adams & Dobson (1984) point out that a moderate degree of connectedness, reflected through shared affection and an acceptance of individuality, provides the foundation and security to begin searching for self-defined commitment. In contrast, weak affectionate bonding with parents and poor communication levels are thought to provide an insecure or constricted psychological base for self exploration.

The impact of HIV/AIDS brings a different contribution to ego or identity formation as it tags along many unfortunate circumstances. Throughout the literature review, HIV/AIDS has been shown to be destructive and dismantling many families; resulting in poor support structure, fragile connections and broken bonds for many adolescent children. Children growing up in weak affectionate bonds, such as those orphaned by HIV/AIDS-related illnesses and lacking appropriate support, are likely to be deprived of a strong, secure psychological base to explore who they are, and to eventually develop what they are meant to be.

The literature consulted thus far strongly points out that the impact of HIV/AIDS on a child's development stretches far to his/her psychological wellbeing, financial stability and security, ability to progress educationally, and it even challenges the child's identity and role in his/her dismantled family. It is said that HIV/AIDS is going to leave many children vulnerable to different negative circumstances, such as the high possibilities of having to bury their parents at a young age, as well as to face bereavement alone. As there is stigmatisation that is often accompanied by discrimination and isolation, such individuals are likely to receive little or no support from their society or the remaining extended families. This is more challenging on a growing child who still requires direction, support and nurturance from

significant people like parents. The challenges faced by such children seem to complicate and even divert their journey to the development of their inherent ego identities, because they don't receive appropriate support that could influence them in a positive way. Many seem to have lost their sense of security and continuity and are already in despair; hence it is feared that some will fall into negative situations such as prostitution, drug abuse, teenage pregnancy or crime. Some are likely to be HIV-infected and thus continue the vicious cycle of HIV/AIDS. According to Erikson, this lack of appropriate context to explore one's potentialities is associated with role confusion as an adult.

The next chapter deals with research methodology.

CHAPTER 3: RESEARCH METHODOLOGY

3.1 Qualitative Research Approach

A study such as this needs the researcher to gain a full understanding of an individual's subjective experiences of HIV/AIDS and its impact on identity development. In this respect an effective research methodology would be the one that takes into account the subject's individual experiences, their interpretation of the event and the meaning it has in their world. A qualitative research approach whose aim is to produce descriptive data and provide people's own written or spoken words and observable behaviour becomes the most suitable for the present study (Taylor & Bogdan, 1984).

Qualitative researchers study entities in their natural settings, attempting to make sense of, or to interpret phenomena in terms of the meaning people bring to them. Moon et al. (1990) makes the point that the researcher attempts to understand the meaning of naturally occurring complex events, actions and interactions in context, from the point of view of the participants involved.

Taylor and Bogdan (1984) provide the following descriptive criteria to define qualitative research methodology:

1. Qualitative research is inductive. Researchers develop concepts, insights and understanding from patterns in the data, rather than collecting data to assess preconceived models, hypotheses or theories.
2. Qualitative researchers are sensitive to their effects on the people they study.
3. Qualitative researchers try to understand people from their own frame of reference. The researchers empathize and identify with the people they study in order to understand how they see things.
4. In qualitative methodology the researcher looks at settings and people holistically. Thus, people, settings and groups are not reduced to variables, but are viewed as a whole.

Rather than focusing on quantitative concerns such as measurement and causal relationship between variables, qualitative research focuses on qualities, processes and meaning people derive from their experiences.

3.2 Rationale for Qualitative Research Approach

Qualitative research approach provides a rich source of information as it allows the researcher to examine a small number of cases extensively (Denzin & Lincoln, 2000). In this case it allows the deepest understanding possible of individuals orphaned through circumstances of HIV/AIDS, and how that experience has influenced their identity development. HIV/AIDS and being an orphan have been shown and described as a growing concern in the country. An in-depth individual understanding of its impact on different levels such as identity formation has, however, not been given much attention. Exploring this issue can give us the opportunity to extensively understand the emotional, mental and physical impact of HIV/AIDS at an individual level and mostly its influences on identity formation.

The qualitative researcher tries to understand participants' interpretation and meaning from their experiences by exploring their social contexts and analysing those interpretations (Tesch, 1990). Although the intention of the study is not to generalise the findings in terms of the larger population, as it does not seek the sole truth or morality of people's experiences, a deeper understanding of such individuals can bring better insight into their experiences.

Qualitative research approach in this study is informed by ideas of postmodernism and social constructionism.

3.2.1 Postmodernism

Qualitative research is often informed by the ideas of postmodernism. Postmodernism is a broad term for many different approaches that set themselves up in opposition to the coherence and rationality of the modern world (Terre Blanche & Kelly, 1999). The modern era was

based on the assumption of the existence of universal truths, and that there was an objective truth which could be discovered by using empirical methods (Furks, 1998). This modern era philosophy ascribes to the view of the world as understandable, controllable and predictable (Doan, 1997). This perspective means that certain stories or knowledge may be rendered invalid if they do not concur with the objective truth or knowledge. It postulates that there is only one truth that each person is measured against and if that person's story or experience does not resonate with the set objective truth, it is rejected or rendered invalid.

Postmodernism, therefore, rejects this assumption of universal truth and objective knowledge. It is based on the belief that there is no universal or objective truth and takes into consideration the ideas of multi-verse of reality with multiple selves, meaning and contexts (Dickerson & Zimmerman, 1996). The essence of postmodernism is one should be observant of any account that claims to offer the sole explanation or interpretation, as many alternative accounts, descriptions or meaning may be possible (Doan, 1997). This approach allows for the expression of many voices than relying entirely as well as measuring one's experience or story on a singular subjective account. Experiences of HIV/AIDS differ in many ways to different individuals, and to subject them to only "one truth" might amount to rejecting one of the individuals' derived meaning and gained knowledge. The meaning derived from different experiences can be understood individually, and is seen as also being influenced by the environment and relationships we dwell in. Postmodernism further maintains that knowledge, or what we believe, or meanings we put, is instead seen as an expression of language, values and beliefs of the particular communities and contexts in which we exist (Lynch, 1997). This postmodernism framework lends itself well with this study as it

allows for the expression of many voices which is what the study intends to achieve. This allows the researcher and participants to fully express their experiences and derived meaning without being subjected or measured against a specific objective notion. It is for this reason that this study is guided by the post-modern approach.

3.2.2 Social Constructionism

Social Constructionism is an epistemology which, like postmodernism, asserts that caution should be given against singular totalising accounts, whose powers tend to further silence and marginalise those whose stories fail to fit. It prefers stories based on a person's lived experience rather than on expert knowledge (Doan, 1997). Social constructionism examines how ideas and attitude have developed over time within a social, community context (Dickerson & Zimmerman, 1996). This is especially so because it stresses the socially constructed nature of reality. This study acknowledges that participants have different experiences with HIV/AIDS from childhood and therefore it is important to understand how their attitude and ideas have developed over time within the environment they were exposed to.

Postmodernism and social constructionism are interested in accounts that honour and respect the community of voices inherent in each individual. In addition, they are interested in helping individuals whose stories have gone wrong or are no longer working, and families whose stories are in collision (Doan, 1997). This perspective helps individuals escape the domination of oppressive domains of knowledge, and contends that we socially construct reality by the use of shared and agreed meaning communicated via language; and that our beliefs about the world are social inventions. Doan (1997) continues to stress that social constructionist perspective is especially interested in the

normative narratives which are formed by, and in turn influence, people. At the same time, people measure themselves against these narratives. This perspective further holds that particular meanings we impose on behaviour are dictated and organised by whatever dominating analogies or interpretive frameworks are currently available. People's personal stories are frequently subjugated and denied in favour of the dominant belief system. The literature review reveals that because HIV/AIDS is largely associated with stigmatisation, affected or infected individuals tend to be isolated and discriminated against. Individual's or group's such as AIDS orphans are often silenced or rejected because their experiences or stories do not resonate with what is defined as normal or acceptable by their community. HIV/AIDS is implicitly characterised by socially constructed ideas which, at the end, influence an individual's interpretation and the meaning derived from their experiences.

This study identifies some socially constructed ideas. One of these is that HIV/AIDS is a taboo, something that we are not suppose to talk about openly because it is an unacceptable disease. The other idea is that orphaned children who grow up without proper parental guidance or guardianship end up being delinquents, a menace to society, and eventually unproductive adults in our communities. Many researches have identified a strong correlation between positive parental influences and matured identity development (Cooper, 1989). HIV/AIDS has exposed some children to the harshest circumstances, leading to broken bonds and a lack of proper emotional support. These children are likely to grow up without proper parental guidance and support from extended families and the community at large. A point has already been made that social isolation or exclusion goes hand in hand with HIV/AIDS. It would be interesting to note how these children have

managed to define who they are amidst the socially constructed perceptions about the impact of HIV/AIDS on these children.

3.3 The sample for the study

There will be three subjects, who are between 18-26 years of age. The participants are orphans who lost one or both parents to HIV/AIDS, especially in their childhood or adolescent years. This is to adhere to the objectives of the study, which is to explore the challenges experienced by children orphaned by AIDS. The age of the participants is relevant in the sense that it allows the researcher and the participants to go back and explore the participants' childhood or adolescent experience. The relevance of this is that it identifies with the purpose of the study; that is, to determine whether their experiences had an influence in their sense of identity. This allows the researcher to adhere to the principles of qualitative research; namely, to focus on the qualities, processes and meaning people derive from their experiences (Moon et al., 1990). The number of participants also represents the style of qualitative methodology which maintains that people's stories should not be reduced to variables or numbers. Their stories should rather be looked at extensively and holistically (Taylor & Bogdan, 1984). The emphasis is on participants who are able to give rich and comprehensive description of the problem under study (Brink, 1991). Therefore, the size of the sample allows the researcher to be able to look at each participant's story in depth and holistically.

Taylor and Bogdan (1984) state that one of the principles governing qualitative research approach is that the results are not generalised to the whole or a specific population. It is in this sense that the participants do not have to be representative of a specific population. In this case the sample used will not represent any specific population

as their results will not be generalised. A convenience sampling was used to select the participants. The participants were identified from the community through word of mouth and were therefore approached for their assistance towards the study.

3.4 Research Instrument

Face to face interviews will be done with participants through the use of a semi-structured interview. An unstructured interview is employed as a way of giving the participants time to express their thoughts and feelings freely. In a qualitative study such as this, a structured interview might limit participants' chance to express themselves and disable the researcher to capture the full experience of the participants. On the contrary, a semi-structured interview offers guidance as to what needs to be focused on, yet allowing the participants to fully express their thoughts. The participants will be interviewed at a venue that is suitable for both parties. The interviews will be taped with the permission of the participants, after which the information will be transcribed, and relevant themes will subsequently be inferred.

3.5 Data Analysis using Hermeneutics Approach

Analysis of information is the process whereby order, structure and meaning are imposed on the mass of information that is collected in a research study. The aim of ordering and restructuring data collected allows for the identification of patterns that are similar or different (Neuman, 1999). In this study the hermeneutic approach will be used to analyse the data collected. Hermeneutics approach is an interpretive approach which comprises a back and forth movement between the studying of parts in relation to the whole, and the whole

in relation to the parts (Denzin, 2000). The aim of this approach is to discover meaning and to achieve understanding, as informed by the immediate context, social structures, personal histories, shared practices and language it exists in (Addison, 1992).

Kelly (1992) points out that interpretive account should not be completely denuded of context, and details should not be presented without being positioned in relation to the overall structure of understanding. This means that the meaning that emerges will be seen as a product of the larger social system in which the participant lives. Kelly (1992), in this regard, states that the relation between the meaning of a particular experience and the meaning of the themes that reflect a coherent ordering of themes of experience represent the operation of the hermeneutical circle.

The following steps of hermeneutics data analysis and interpretation were adopted from Terre Blanch & Kelly (1999).

3.5.1 Familiarisation and immersion

This step involves a focused reading of the research transcripts so that the researcher can immerse and familiarise herself with the world of the participants. This allows the researcher to have a holistic view of the data. Although the researcher already has ideas about the themes of the data, she firstly tries to understand the participant's view of their world by reading and re-reading the texts.

3.5.2 Thematising

This step involves extracting or identifying underlying themes from the material and finding examples in the material that fit under the researcher's predefined categories. The researcher achieves this by

highlighting or underlining certain phrases and instances from the data, she notes down any relevant comment or corresponding themes that stood out.

3.5.3 Coding

The coding system entails re-examining the data with intention of grouping together related and similar phrases, paragraphs and instances which are relevant to one or more of the themes, under the same theme. At this stage the researcher is advised to look for meta-themes in the material where various or sub-themes may be clustered together under larger themes (Terre Blanch and Kelly, 1999).

3.5.4 Elaboration

The process of elaboration allows the researcher to constantly re-examine and alter her coding system, therefore the identified themes may be structured and restructured several times in order to accommodate new findings. This step involves capturing the hidden, deeper meaning, misunderstandings or alternative meanings from participants. Terre Blanch and Kelly (1999) suggest that the researcher keeps on elaborating and recoding the data until no further new information emerges. During this stage the researcher engages in a hermeneutical process of moving back and forth between parts of the story and the whole story in many cycles until a deeper and clearer meaning and understanding is derived (Terre Blanch & Kelly, 1999 and Tesch, 1990).

3.5.5 Interpretation and checking

At this final step, the researcher gives a final written account of the topic she has studied. Excerpts that have been selected from the data are woven into the interpretation in order to substantiate the identified themes and provide a clearer account of the participant's experience. The goal of the researcher is to provide a description of each of the participant's experiences in order to understand each of their perceptions. The researcher constantly reflects on her role during interpretation of data and how she may have influenced data collection and interpretation.

3.6 Ethical consideration

This study took into consideration certain ethical issues that need to be adhered to. Firstly, researchers are required to safeguard all their dealings including the recording and dissemination of confidential information about their research participants. They are also obliged to discuss with the participants the limit of confidentiality, including the disclosure and release of confidential information the participants reveal to the researcher (Health Professions Council of South Africa, 2006; Oliver & Van Der Walt, 1996).

The issue of confidentiality and respect to the participant's privacy has been observed throughout the study. The researcher was aware of her responsibility to protect the identity of the participants. To adhere to this principle, the participants and their family members were given pseudo-names. This is especially important because the nature of the study deals with sensitive issues around HIV/AIDS and therefore the researcher and the participants felt that the participants needed to be given privacy as well as be reassured of confidentiality. Participants were also informed about the purpose of the study and the way the research results will be handled, up to the stage where they will be

made accessible to the public. Therefore they were reassured of confidentiality but also given the option of not being involved if they feel uncomfortable.

Secondly, the researcher is required to obtain informed consent from participants in order to participate in the study (Anastasi, 1976). According to the Health Profession Council of South Africa (2006), the informed consent should use the language that is reasonably understandable to that person. The contents should also explain all circumstances that might affect the participant's willingness to participate in the study and they should also be made aware of the voluntary nature of participation. The above obligations were adhered to in this study. It is in this respect that written and expressed consent was obtained from the participants.

Thirdly, the researcher noticed that the interview raised many sensitive feelings that required the researcher to be mindful of and also to be able to help. The environment created enabled the participants to talk openly and share their pain and hurt but, in the main, it created a space to say things that they felt they could not, otherwise, say to other people. In addition, the researcher's role as a therapist allowed the containment of painful emotions, and addressing them before continuing with the research process. The participants were advised to join the support centre for AIDS orphans and other vulnerable children in their community in order to get the support that they needed to alleviate their struggles in other areas.

In conclusion, this chapter focused on the methodological approach that would guide the rest of the study. The chapter gave the rationale for the qualitative research methodology and how it will be applied in order to produce what the researcher intends to bring across. The

application of this research methodology will be reflected throughout the next chapter, which deals with research results.

CHAPTER 4: RESEARCH RESULTS

4.1 Introduction

This chapter will discuss the research results of the three research participants that took part in the study. These participants are children who have been orphaned by HIV/AIDS. Essentially, the report is based on the experiences that these children have had; particularly as they relate to the development of their identity. In line with the study's objectives, the following are reported on:

- The experiences of being orphaned by HIV/AIDS
- Whether these experiences have an influence on AIDS orphans' identity development
- How these experiences influence the identity development of AIDS orphans

In reporting the results of the study, specific themes that have been identified from each participant's story will be used to highlight the specific psychosocial issues emanating from participant experiences.

The researcher used themes as elaborative tools to give detailed descriptions of each participant's experiences. They are also important for this study because they assist in further elaborating on many of the issues that have been raised throughout the research literature. They provide a link between what was highlighted in the literature review and the actual events that occurred in the participant's lives. Each participant's experiences will be presented separately according to these identified themes.

4.2 The results of the study

4.2.1 The Story of Lucky

4.2.1.1 Biographical Information

Age: 26 Years Old

Gender: Male

Level of Education: Grade 12

4.2.1.2 Family background

Lucky Mbelu was born in Tembisa where he had lived with his mother and younger sister. Lucky's mother started being sick almost two years before her death in 2000. At that time, Lucky was 17 years old. Mrs. Mbelu was a single parent. Lucky reported that his father had not been present in their lives since he separated from his mother. He subsequently abandoned his responsibilities as a father. After the death of their mother, Lucky and his younger sister were taken to live with their aunt (his mother's older sister) in Tembisa. They currently

stay with their aunt, her husband and their four other children. Lucky completed his matric and wants to pursue a career in the performing arts. Currently, he is still at home because of a lack of financial support. He believes that getting a job will help him get where he wants to be.

Lucky's experience as a teenager orphaned by HIV/AIDS has raised many issues that still affect him, and influence his life up to this day. In the following discussion, the researcher extracted some of the psychosocial issues from his story in order to fully understand what he went through. The psychosocial issues will be elaborated further in the themes below.

4.2.1.3 Psychosocial Issues

4.2.1.3.1 Material support and dependency

The theme of material support and dependency was seen as significant in Lucky's story. In this instance, the theme of dependency refers to being reliant on others as opposed to being reliant on oneself, and how that impacts on, and influences one's future. The relevance of this theme in Lucky's life is that he speaks of the need to be independent rather than being too dependent on certain people and even other things or materials to explore and develop who he wants to be. Lucky believes that the support he would have received from his mother would have made considerable difference than the little or no support he is getting. He believes that it would have laid a good foundation for him to develop that sense of independence he wants as young man.

He described the relationship he had with his mother as the kind that allowed him to be free in terms of expressing his needs and ideas about his future, as opposed to being unable to open up about his needs to his aunt. He perceives the relationship with his aunt as lacking the appropriate emotional and financial support that he wishes to have.

Lucky believes that his mother's passing has played a role in how his life has turned, especially in terms of receiving emotional and financial support. In his story he insinuates that he would be a more self-dependent person because his worries and needs would have been appropriately provided for, rather than being his primary concerns and obstacles towards his success. Lucky believes that being part of a large extended family also makes it difficult for all the children in the family to receive proper material support and a good foundation to start developing their future.

Lucky believes that his future is threatened because it is largely determined by the extent of his dependency and lack of support from significant others. In the interview he emphasised that he does not see how they will all be able to get the financial support they need because they are already too many for her aunt and her husband. He said:

I am not sure how my future will look like for me because we are too many at home, how will they support each one of us financially. I just don't think that we will all get the financial support we need and that worries me because it means that we will have to see how we make it in life.

His expressed fear is that he does not see how his aunt and her husband will be able to provide further for all of them. He seems

worried that this situation will prolong his dependency and lack of progress with his life. Lucky also pointed out that apart from his concerns about financial security and support, the relationship with his aunt seems distant and not open. He said that she appears uninterested in his life and that makes it difficult for him to open up to her about his needs. He said that he did not feel that the relationship with his aunt made him feel free to ask for important things like money or clothes in order to be able to pursue his dreams. This is what he said:

I don't feel free to ask her for anything, even important stuff because at the end she is just helping us survive. You know with your mother you can ask for anything but I would hold back when it comes to my aunt.

Lucky expressed that one of the challenges he faced in his quest for independence was trying to pursue a career as a performing artist. He described how difficult it was for him to pursue this dream especially that he had to rely on other people for assistance. He feels that the lack of significant aspects like transport money or appropriate dress for certain occasions impede his chances of exploring and expressing himself. To him, such things appear to be key towards his future. He is mainly worried that his dependency on other people and certain things will continue to be an obstacle that will keep him in the very same situation he wants to come out of, and will eventually create a vicious cycle in his life. In this respect, he said:

Like this dream of being a dancer, I depend on whether there is money for transport or the right attire there is always something I have to produce in order to get in. I feel like I am not faithful to myself because I am living according to what other people are

offering me. Until I can get something from this one it is then that I can take a step ahead

The theme suggests that Lucky might be feeling stuck and handicapped by his situation. This seems to raise uncertainty, fear and worry about his life. He fears that the more he is dependent, and lacking the necessary support, the more it became likely that he will be unable to be a self-dependent adult. Hope for education and a better future also seem to fade away as he sees how difficult it is to get his feet off the ground.

4.2.1.3.2 Education and outlook on the future

It has been indicated throughout the literature survey that many children affected by the impact of HIV/AIDS are likely to experience difficulties in completing school and continue with higher education (Kelly, 2004). It has been indicated that many factors surrounding HIV/AIDS are likely to compromise the future of children affected by HIV/AIDS. Some of the reasons why some AIDS orphans' education and schooling are compromised are (i) losing a parent who is the only breadwinner in the family, (ii) having to care for a sick parent, (iii) being unable to continue with school and (iv) being thrown into home of extended families that do not necessarily have the child's interest at heart. Lucky seems to fit clearly into this description.

In his story, Lucky felt that he needed more than just accommodation and food in his life. He repeatedly spoke of the need to have material support and to further his education and dreams. He believes that having the opportunity to further his education and achieving his dream of becoming a performing artist would enable him to redirect his life according to the way he always wanted. However, he felt that

most of his needs were not met because he did not receive proper attention and support from significant people in his life. He said he did not receive proper attention, so that he even felt misunderstood and not taken seriously. He inferred that his family were disinterested in what he wants to be. This is what he said:

Sometimes I feel misunderstood. The people I live with don't understand me like my mother used to. Like this dream of becoming a dancer, they don't believe that it is something that I can do and be successful. I think I can do it but I don't get support from my family.

He believes that no one cares about his dreams, and nobody takes the time to ask and listen to what his plans for the future are. It seems he is disappointed that no one believes that he can make a successful career as a performing artist; hence he does not get the support that he needs.

The other challenge that made it difficult for Lucky to get the support that he wanted was the resentment he felt from his cousins; that is, his aunt's children. He felt that his cousins felt deprived of certain things, and now had to share certain things among all of them. That made them unhappy. He believes that his cousins saw him as an additional burden to their parent's list of responsibilities. This appeared to confirm that he was not allowed to ask for more than what he was given, and that he should be content with what he got. The thought that they were too many for his aunt to meet all their needs has also crossed his mind. He thinks that their chance of achieving their dreams is already compromised by the fact that they are now six children who all expect to be given an opportunity to fulfil their dreams. Lucky felt that his aunt was overburdened by the expectations and

responsibilities towards all the children, and it would have been easier if his mother were alive. He believes that she would be able to dedicate all her efforts and finances to him. He expressed this view thus:

It would be easier because she would put us first in her priorities. We won't have to share money or clothes among the six of us like now. I don't think she was going to give us much, but I think she could be able to give us a better chance in life. I could have a better chance of following my dream or trying to be the best I can be and not feeling the pressure to look for a job like now.

Due to these circumstances, Lucky had mixed feeling about his future, when he said:

I am not sure how my future will look like for me because we are too many at home, how will they support each one of us financially. I just don't think that we will get the financial support we need and that worries me because it means that we will have to see how we make it in life.

In this theme, Lucky emphasised how important it was for him to have support in every area of his life because that was a determinant factor to what he wants to achieve in his life, and influenced his outlook of the future. He perceives the lack of support as having a negative impact on his future, especially with regard to his education and the development of a stable career.

4.2.1.3.3 Parental love and care

This theme forms one of the psycho-social issues that Lucky had to contend with when his mother died. Like the previous themes, this

theme also emphasises Lucky's need for love and care as a child. He spoke constantly about how his mother had loved and appreciated him and his younger sister when she was still alive. It seems the early death of his mother raised feelings of being deprived of motherly or parental love and care when he grew up. Landman (2002) maintains that there is a high possibility of a growing generation of young people left to their own devices with no appropriate parental care, love and guidance, even no natural affection. In this respect, Lucky said: *"I just feel like I am missing something, something that parents give to their children like love and support"*.

He stated that as a child growing up he needed to hear and see that there was someone who loved him, and who showed that he was thinking of him. He believes that among the things he needed as a child, love was more important to him. He said:

As a child you need to feel like someone loves you very much because you are a child and that's all you know you need, love. Love is more important than anything for a child.

Throughout the interview, his emphasis was that although he got some kind of support from his aunt, he still felt that he was not getting motherly love from her. He stated:

I miss a mother's love and care. I miss being free and not being too dependent. My aunt provides for us very well but I don't see or feel her motherly love towards me.

Lucky sounded unhappy about his aunt's role in his life. His view of his aunt is that of someone who is mainly concerned with some of his material needs as opposed to his needs as a whole. This appeared to

have a significant impact on Lucky's relation to his aunt. It seems he felt emotionally distant and disconnected from his aunt because of not feeling affection and appreciation as a child. It seems that this expected motherly role that Lucky's aunt has been thrust into, in conjunction with the expectations and needs that Lucky has, is an issue that is yet to be reconciled. The relationship with his mother seems to have been characterised by love, care and support. There was a certain level of closeness and emotional connection between a son and mother that Lucky still yearns for.

4.2.1.3.4 Isolation and sense of disconnection

This theme appears to be influential in Lucky's life because his story shows how he has been made to feel unwelcome by his extended family ever since the death of his mother.

In this instance, the theme of disconnection refers to a feeling that one is not part of a certain system or unit such as a family or community. Isolation refers to being distanced (physically and/or emotionally) in which respect one feels like one is not part of a certain system or unit like family or community.

This theme seems to resonate with Lucky's experience. He told about his painful experience of being distanced and isolated in the home of his extended family when he moved in with them. He felt that the family was often cold and uncaring towards him. That made him feel emotionally and physically isolated from them. This experience made him feel isolated and distanced from the whole family. He said that he did not feel like he belonged. He expressed this view thus:

The other thing is that I did not feel like I belonged because I think her children don't really like the fact that she (aunty) is taking care of us. I think they were feeling like we are depriving them because certain things had to be shared among all of us and that made them unhappy. It was hurtful because I think they resent us and they don't treat us very well. The thing that hurt the most was that aunty does not really intervene and her husband always took his children's side.

He feels that the way his aunt and her husband handled conflicts between him and his cousins just confirmed that his feelings and thoughts were not that important to them. In Lucky's view, his aunt and uncle did not really intervene to help solve fights or problems between him and some of his cousins; but when they do, they usually took their children's side. It seems that he felt rejected by the family; especially the way conflicts and tension were handled. This made him feel more disconnected from them. He feels isolated and distanced when his worries and pains are not listened to. In this regard, he recalled one incident:

The other time I was taking a bath and she wanted to get in the bathroom by force, as if I was not there. She always looks for ways to disrespect me. She says that I think I am now the man of the house and that I have forgotten myself that her family has given me a favour by giving me a place to stay.

He said that when he tries to open up and express his worries, his aunt or uncle says that he is the oldest and should know better. For Lucky, such instances added to his withdrawal, and ultimately to his feeling of being disconnected. He felt as though he was not part of the family.

Lucky sounded worried and concerned about his situation. He added that he even felt uncomfortable to bring his friends for a visit to his home because they might also feel uncomfortable being there. He expressed this view thus:

That's why I want my friends to feel loved and welcomed in my home, but now I can't bring them too often because I am afraid that they will see that they are not welcomed. If I don't feel at home then they will feel that they are not welcomed to their friend's home.

Lucky's complaints about the level of disconnection he feels show how he yearned to belong and to feel that someone took his feelings and thoughts into consideration. It also seems that feeling isolated and disconnected from the rest of the family raises feelings of loneliness and uncertainty because there is no reassurance of support from the rest of the family.

4.2.1.3.5 Stigmatization and Discrimination

The theme of disclosure and stigmatization is discussed because Lucky's experience towards the death of his mother highlights certain perceptions that are often associated with the continuing veil of secrecy, fear of stigmatization and rejection that surrounds HIV/AIDS-diagnosed individuals and those affected by it.

Stigmatisation refers to perceptions and feelings of being labelled in a negative way because of being associated with inappropriate or unacceptable behaviour. In this instance, an HIV-positive individual is labelled in a negative way because HIV/AIDS is associated with unacceptable or promiscuous behaviour such as prostitution or drug

abuse. The individual might be subjected to discriminatory behaviour by others because of the influence of stigma.

During the interview, Lucky mentioned that he did not know of his mother's HIV status:

I did not know for sure what was wrong with her. I did not know that she was HIV-positive until she passed away. The day she died was the day that my aunt told me that she had AIDS; that is why she passed away. All I knew was that there were problems with her womb, nothing much. She kept it to herself (her health concerns) and I did not want to ask her about it because I thought that it was women's stuff.

Lucky and his mother had lived together in the same house, but it was never easy for his mother to talk about her HIV-positive status with her children. Even though Lucky's mother was unable to disclose her status to his children, he also expressed his own discomfort of talking to his mother about her health. He said that he was shocked and also hurt to discover that his mother's death was caused by AIDS. He said:

It hurt me to hear that she had AIDS because I did not expect it. It never crossed my mind that it will catch someone so close to me so I still have difficulty accepting her death.

Lucky was not only hurt by the shocking discovery of the cause of his mother's death, but also how he came to know the truth about his mother's health status. He sounded shocked that his own mother had had AIDS. It was even more shocking, especially because she was very close to him. The shock seems to have resulted from the fact that he could not understand that an issue like HIV existed in his own home.

The effect of this was that apart from dealing with his mother's death he still had to accept how she died. Lucky was also concerned and bothered by the perceptions his community had about HIV/AIDS.

Lucky is of the view that the community he comes from is not very accepting and caring towards anyone infected or affected by HIV/AIDS. His perception about his community is that people tend to assume that you have HIV or AIDS once you start getting sick. He seems to think that the impact of the stigma associated with HIV/AIDS has made people to be quick in judging, and discriminating against, the person than to take the time to know and understand the reality. From his experience he said:

Here in Tembisa, once you get sick people already think that you have AIDS or HIV, especially if you get thin. Even though they don't know what is wrong they won't ask you.

He sounded disappointed with how people in his community tend to react to individuals affected and infected by HIV/AIDS. On this account, he believes that his mother, by not disclosing her status, was protected from such opinions. His belief seems to be that his mother was distanced from harsh judgements and ill treatment by not disclosing her status to everyone. It sounds like he acknowledges his mother's decision to keep her HIV status a secret. In his opinion, his mother was justified to do that because of the negative perceptions and stigmatisation he has already encountered in his community. It seems there is great fear of rejection and isolation on the part of the people affected and infected by HIV/AIDS in his community. In this regard he said:

I could understand why she did not want to talk too much about it, because I can see that people in our neighbourhood can

gossip about you and can reject you when they think that you have AIDS.

His thoughts appear to be influenced by the fear of rejection and isolation by neighbours. He creates the impression that not talking about HIV/AIDS reduces the impact and chance of being stigmatized and rejected by your community and those closest to you. The meaning he derived from his mother's experience regarding her HIV-positive status was that being secretive about one's status somehow provides protection from harsh judgment by other people.

In Lucky's view, being rejected and stigmatized by the community appears to be more difficult and painful to deal with than disclosing one's status. It appears to be a good enough and justifiable reason not to disclose one's status. He also thinks that knowing the HIV status of his mother after her death was better, because he did not have to deal with opinions of other people and he would not feel too preoccupied by worries over his mother's health and other people's opinions. On this point he said:

It happened and maybe knowing her status after her death was better because I did not have to worry about what other people think. But I was hurt by the whole situation.

He also thought that his mother kept her status a secret because she didn't want them to be too worried about her. Lucky seems to think that she wanted to protect them.

This is captured by the following comment by Lucky:

My mother was not open about her illness. I think she did not want us to get worried about her. She wanted us to feel like she will always be there for us. She would make sure that she tries to clean and cook for us so that we won't see how sick she was.

He also believes that the family knew about it, but they did not want him to know about it. They generally did not want to talk about it.

The events from Lucky's life show the discomfort and secrecy that still surround HIV/AIDS and those affected and infected. The impact of stigma still appears profound and makes it difficult to break the silence about HIV/AIDS. Lucky's encounter with HIV/AIDS issues shows how matters like disclosing an HIV-positive status can shape and direct one's life. Lucky's mother had distanced herself from her family and community. This left them isolated and alone. It is possible that this reality also limited the amount of support they could have received from others. However, the fear of stigma and rejection seemed more overwhelming. Now Lucky's attitude and perception towards HIV/AIDS is clouded by fear. He consequently believes that it is better not to disclose so as to avoid being stigmatised and rejected.

He feels that the experience he went through has affected him in different ways. His thoughts about certain issues in his life have been greatly influenced by the experience he faced during his teenage years. In the following theme he speaks about the impact of his experience on his identity.

4.2.1.3.6 Ego Identity

The discussion of this theme endeavours to shed some light on Lucky's sense of identity with regard to his life experiences.

Ego identity is described as a person's perception of his/her true self. It is a process seen to be influenced by one's inherent desire and need to develop and/or acquire a stable role in his/her society. The process of identity development is said to be influenced by the support from one's significant others, such as family or community (Engler, 1989). In contrast to "Ego Identity", there is "Role Confusion" which Erikson refers to as a difficulty in acquiring a stable sense of identity and role as a person in one's community or family (Meyer, 1989). In his narrative, Lucky talks about how he is struggling to define his sense of identity.

As seen from previous themes, he talks about his family's poor emotional connection, lack of support and feelings of isolation that he believes affected him and his self concept. He believes that he does not live according to his true self or desired self, because his life is guided by what other people are offering him, rather than what he really desires. He seems to feel that he has limited control over his destiny and therefore cannot be who he believes he ought to be. He describes himself as someone who just survives, and has limited control over his future. He said:

I see myself as a person who just survives with what he has today. I don't know what tomorrow will be like for me, so I live day by day. I don't feel happy about myself or my situation because I am not sure where I am going.

Lucky sounded unhappy about his situation as it does not represent how he wants to spend his life. He felt that there were many uncertainties in his life when he grew up, and that seemed to affect his future. Not knowing what tomorrow will hold, seemed to make it

difficult to have stability and direction about his future or to define a clear role for himself. He acknowledged that he is not living according to his true self when he said:

I feel like I am not faithful to myself because I am living according to what other people are offering me. Until I can get something from this one it is then that I can take a step ahead. Like this dream of being a dancer, I depend on whether there is money for transport or the right attire, there is always something I have to produce

From this piece of narrative, it is apparent that he believes that his role confusion is influenced by the thought that he is not being faithful to himself. His current self-perception seems incongruent to his true self. This might mean that he is still searching for that balance in his life. He believes that he became who he is today because of what was available for him when he was growing up. He suggests that his present identity was predominantly guided by what the outside environment had to offer him. It was mainly influenced by the need to survive in his environment, and not necessarily by what he wished to be. He insinuates that he was handicapped by the level of dependency on others. As pointed out earlier, this made it difficult for him to explore and discover who he really wanted to be.

It has also emerged in the discussion of the previous themes that he where he indicated that he cannot pursue his dream because he is too dependent on certain people or things to be able to succeed and show his potentialities. Lucky also feels that as a 26-year-old, unemployed and not continuing his studies, this situation puts him in a disadvantaged position. The situation he grew up in somehow restricted him to explore and challenge his true potential. He says that

he has to be reliant on his aunt for many things, but he cannot just ask for anything because she has her own children. He feels uncomfortable asking for certain things from his aunt because she has already provided many things for him. He says the fact that she is not his mother will always put a boundary between them. He believes that the state of their relationship somehow affects his ability to express and explore certain things about himself, and to develop his true self identity, because he feels that his aunt does not really take time to know and understand him. He seems to believe that his aunt does not take time to listen to what his real needs are; hence, there is no encouragement from her. It would appear that he also desires to have parental affirmation and encouragement about his life from his aunt. He regarded his mother as a person who would encourage and affirm the decisions that would help to develop him. He described his mother thus:

My mother is a person who would listen and encourage you to be what you think you can be. My mother was a thoughtful person who encouraged us to be what we thought we can be good at. Yes, maybe if I had better support at home I would be able to do the things I enjoy and maybe I would have achieved more than today. Now I am really not sure of my future. Maybe if I was sure of my future I would be surer of myself. I mean if you have parents at least they can somehow help you go far. Parents can give you a better chance in life than any person just because you are their child.

He believes that the death of his mother has influenced his perception of himself, because he experienced their relationship as full of love, care and encouragement. It seems her presence had been reassuring and also stimulated him to try to be what he wants to be. He said that

even though his mother did not have much, she had encouraged him to always be hopeful. He felt that his mother was interested in his life and his future hence he felt understood. He believes that the close relationship they had had, as well as the emotional support he received, encouraged him to be the best that he wanted to be, and to try things he thought he could do.

Lucky wishes that his relationship with his aunt was more than just someone giving him physical needs like a home and food, and also have a good emotional connection. He was not satisfied with the kind of support he received from his aunt. He considered this to be an obstacle to developing his true identity because he needed love, affirmation and encouragement when he was growing up. He believes that the death of his mother took this away.

In this regard he said: *“My aunt provides for us very well but I don’t see or feel her motherly love towards me”*.

This theme expresses the dissatisfaction and unhappiness that Lucky feels about himself, his future prospects and the kind of support he is receiving from his environment. He believes that he is not a confident person and also that he does not live according to his true self. He feels unhappy that he has not discovered who he really is and that chance is jeopardized by a lack of proper support from significant others and his environment. He currently describes the characteristics of his identity as being dependent and lacking confidence. He says it (his identity) has been influenced and constructed more by forces from his external environment than from his inner desires. He believes that the lack of motherly love and encouragement played a major role in the development of who he is currently. He lacked a strong support base from significant people to help him commit to a desired self-identity. The inability to further his career or studies and being

unemployed also confirmed his inability to be a productive member for his family and community. He feels that he is still searching for his true self, that which reflects the person he really is.

However, Lucky believes that even though he is not sure of what the next day will be like, he is proud that he is able to take each day as it comes. He is encouraged to live on. He perceives this aspect of his character as his strength.

4.2.2 The Story of Sibongile

4.2.2.1 Biographical Information

Age: 26 Years Old

Gender: Female

Level of Education: Grade 10

4.2.2.2 Family background

Sibongile is the second participant in this research study. She is 26 years old, and has a two-year-old son. She currently lives with her two sisters, Linda who is 29 years old and Thandeka, who is 24 years old. Both Linda and Thandeka have two children each. They have been living together since the death of their mother in 1998. According to Sibongile, their father has not shown interest in their lives since they

were young. She said that the other thing that keeps him away from them might be the fact that he lives with another woman, with whom she has two children. Sibongile is currently looking after her son and is unemployed. She said that she relies on her child's grant and her boyfriend to provide for her basic needs. She left school when she was 17 years old, whilst doing grade 11. She dropped out of school because she had to take care of her mother when she was sick. She was unable to resume school ever since. Her elder sister, Thandeka, left home in 1996 to look for a job in Alexander and never came back. She left her sickly mother with her younger sisters to live with her boyfriend. She only came back when she heard about the death of her mother. The major responsibility was therefore left with Sibongile at that time. She tells about the challenging life experiences she had to endure: from taking care of her mother, to leaving school and being a parent at a young age.

4.2.2.3 Psychosocial issues

4.2.2.3.1 Material support and dependency

As Sibongile recounts her life experiences, she emphasised the need for her to feel independent and in control of her life. She says that she feels too dependent on other people. As a result she feels insecure and uncertain about herself and the future of her child. She feels that she is unable to properly provide for her child and herself, and this worries her as that is not what she wants. It would seem that her fear is that she might end up being nothing, and having nothing to give to her son. In this regard she said:

I feel that I don't have security in my future because I depend on other people and that is what I am worried about, that I will just be no one with nothing, nothing to give to my child. I can't really say that I provide for myself and my child right now. I just depend on other people like my boyfriend or my aunt or my sisters.

This suggests that her outlook on the future is surrounded by fear and uncertainty due to a lack of security for herself and her son. Sibongile sounded very concerned about the way she is so dependent on other people. She thus does not like the idea of relying too much on her boyfriend or sisters forever. It appears that as she grows up, there is also pressure and the need to stand on her own in order to be able to provide for herself.

She added that the death of her mother has played a major role in her life in the sense that she had to make some difficult decisions that changed her life's journey. When asked about it she said:

I think so because now the situation I am in and everything that has been happening in my life so far is because of not having support from parents when I was growing up and not being sure of the future. I think if my mother was alive I don't think I would really feel pressure to move in with him (boyfriend). She would give me that support that I now get from the outside. I think she would help me make a better life than the one I am living right now. Because I am not really happy with the life I am living now and I don't think it will really change a lot in the future.

She believes that she was compelled to take the decision of seeking support outside her home, which at the end made her unhappy. She

said she reluctantly decided to let her boyfriend move in with her, because she felt that she needed someone to help her. Sibongile said she believes in marriage and she would have liked to be married first rather than just moving in with a boyfriend. On this point, she said:

I am sort of forced to be in this situation I am in with my boyfriend. Like I was saying, I don't want us to just move in together especially in my parents' home. I want to get married, buy a home for our children, but I can't do it on my own. I need support and help is good. I think if Mama was still alive I would not feel the pressure to move in with him.

She feels uncomfortable with the idea of letting her boyfriend move into her home especially that they are not married. She would like to see herself as someone who would be able to stand on her own, who is independent and able to create a decent life. Apart from this, she thinks that people close to her have become judgemental about her for allowing her boyfriend to move in with her in her parents' home. They are suspicious that she might be using him for financial support.

In a response to an interview question, she said:

That is why I worry that people think that I just took my boyfriend to my home without getting married first. I don't want people to always think that I took him for his financial support. I also want to do things for myself and for my child. So, right now I feel too dependent on others and I am scared that this might be my future, it can be this way for me for some time.

Sibongile also said that the decision to leave school was mainly forced by circumstances around her. She said that she had to leave school to

take care of her mother because she was the only one who could be available to do so. She believes that this has also compromised her future prospects as she was unable to complete high school education. She believes that this will always be a huge challenge, because education forms an important part of creating a better future.

Sibongile also feels that not being able to do things for herself put a dent on her character and role. In this context, she remarked:

I want to be able to take care of myself and do certain things for myself and my child. I want to do things for myself and not to wait for other people to do things for me because you never get a chance to grow up. You always feel like a child because you are too dependent on other people.

It would seem that she needs some freedom so that she can take certain decisions or do certain things without being compelled to go through other people first. She seems to think that if she can stop feeling like a child, she can start to feel and grow up to be a confident and independent person because of the authority and control she will have over her own life.

She expressed this view thus:

I want to be happy and I think if I am independent I can be happy and confident. I think when you can't do things for yourself, you are not really in control of your future and therefore you can't be confident in yourself. So I want to be confident and independent.

Sibongile thinks that for as long as she feels too dependent on other people it will be difficult to acquire that desired state of independence. She seems to feel that her life is clouded with uncertainty, and lacks

guarantee that her situation will change significantly. Her need for control and authority over her life are very important because they seem to serve as measuring tools towards her progress in life, and the development of positive self-confidence. She also thinks that being independent and having a secure or better life also contributes significantly towards one's journey towards self-discovery and self-identity.

4.2.2.3.2 Education and outlook on the future

Sibongile expressed how difficult life became when her mother became seriously sick. It was even worse after her death. She said that they had to rely on their aunt to help them get on their feet because the money they were left with after their mother's funeral was not enough. Even the surplus that was left was used for the funeral. She said they are still struggling to recover from their loss. She captured this sentiment thus:

It was a difficult time for me. It was not easy; even today I am still struggling to put my life together. For my sisters as well, things are not going well. We are all struggling to cope because we need things like food and clothes.

Sibongile felt that they needed some assistance with certain things in order to survive. She said that she had to find ways or means to provide for her needs. She said that apart from the help she got from her aunt and boyfriend, she had to rely on her son's social grant to meet her needs because she is unemployed. She said that it is difficult for her to find a job because she personally has to take care of her son as she cannot afford day care services.

Although she sees that hers is a situation of dilemma, she believes that she can only be out of it through finding a job and completing her matric. However, this is even more difficult when she still worries about basic things like food and clothes. She said, *"Sometimes even worrying over food and clothes can make life difficult, but having parents or someone worrying about things like that can be helpful"*.

She had to take care of her mother when she was sick and therefore could not continue with school anymore. She felt that her mother's illness and death from AIDS affected her schooling, because she was the only one available to care for her mother. Even after her death she still could not continue with school because of a lack of financial support.

Though she appreciated the importance of school, her situation forced her to drop out. She said that she did not feel too bad about it because there was nothing she could do under the circumstances. She felt that it did not really matter if she did not go to school because she witnessed how her mother was struggling with her illness. In this respect, she is convinced that taking care of her mother seemed the right thing to do at that time. She had hoped that her mother was going to get better soon, and she would thus be able to resume school later. Unfortunately, everything changed for the worse when her mother died. She said, *"It was going to be nice to have someone helping me because I could not continue with school."*

Sibongile felt that the support they were getting was not enough. She felt that her other aunts were not really supportive because they did not show their support from the time their mother was sick and only came during the funeral. She also thought that her neighbours were similarly not very supportive during her mother's illness. Instead of being helpful, they rather became distant and judgemental towards

them. She said that people who had been close to her failed in some way to give them appropriate support and care.

In many aspects Sibongile believes that being orphaned at her age affected and influenced her current circumstances and her future. Her opinion seems to be that having appropriate support and the opportunity to complete school would have made her future prospects better. Although being able to complete school was important for her, she considered parental love and care to be significant as well.

4.2.2.3.3 Parental love and care

Sibongile said that the greatest thing she missed most in her life was her mother's presence and the motherly love she had had for all of them. The theme of parental love and care reflects how HIV/AIDS death has continued to deprive children and parents of fulfilling relationships. Upon the death of her mother, Sibongile felt that she missed having her mother in her life and her genuine love and care. She feels that since her mother's death she has not experienced the kind of love her mother showed her and she has not seen anyone truly interested in her life the way she was. This became evident in the following remarks:

I miss her presence and her real love for us. She was a real mother to me. I miss having a mother, someone who truly loves me and cares about my life.

Her belief is that parents can give their children a sense of financial security and support because they may provide certain things for the child to pursue his/her dreams. She feels that the loss of her mother has made her feel that her future dreams and possibilities were compromised because of the lack of financial support she needed

when growing up. She said that her mother did not have much, but she had been interested in their dreams and had tried to do her best to provide for their needs. She added that the necessary parental support. She described her as a good mother who had tried her best to give her children a good life. Sibongile strongly feels having AIDS did not change who her mother was. She always valued her opinion and continued to give her the respect that she deserved even though there had been rumours that she had AIDS. She said that because she had always been a good loving mother, it became easy and right for her to continue seeing her as a good mother. Her description of her was as follows:

Mama was a good person who cared for us very well. She is still our mother and I will still give her my respect, having AIDS does not change anything about her. She was a good mother to me.

During the interview she continued to emphasise that she also needed motherly support and advice as a teenage girl growing up to be a young woman. She believes that every child needs to have a parent who can guide him/her through life. Parental advice and support are so crucial because parents have life experience. The following remarks bear evidence to this sentiment:

I think every girl should have a mother to support and advice her. I think it would be nice to have someone warning you of certain things, someone who can tell you that it is wrong to go that way and show you which way to take. Every child needs a parent because parents have experienced life so they know how to handle certain things about life and they can share those experiences to help you.

Sibongile thinks that having parental love and care as a child or teenager can make life easier because then there is reassurance for support and provision on different levels. Her belief is that:

A parent can make it easier for you to face the future because they are there for you. They somehow take worries about certain things away because they make it easier for you to focus on school and your future, and they focus on providing the things you need. Now it is very difficult for me to focus on all those things because it is stressful to know that I am not really going anywhere. Having a parent can take that stress away.

Among the things Sibongile felt she needed her mother's support with was raising her son. In this sense, she said:

I wish she was here with me when I had a child because it was difficult being on my own during the first months after birth. Even during my pregnancy because you don't know what to expect. It was scary and her support might have helped me to relax, not worry too much. I also wish she was here to see her grandchild and to help me raise him.

Sibongile felt that her need for parental love, care and support extends beyond her only, because she feels that her son also needs his grandmother's love and care. She maintains that her mother's early death from AIDS deprived her son of having a relationship with her grandmother. She also feels that her mother's support during the pregnancy and birth of her son would have also made a considerable difference in her life. She said she had felt alone and needed some kind of support and reassurance during her pregnancy, because she was unsure of what was going to happen.

Sibongile also said that she needed her mother more when she was growing up because she could not continue with other important things like school and further education. The fact that she could not continue with school seems to have added to the sense of disconnection with other people like friends and the community. The next section discusses the theme relating to how HIV/AIDS can create the sense of isolation and disconnection from others.

4.2.2.3.4 Isolation and sense of disconnection

The theme of disconnection has been identified from Sibongile's story. In this instance, disconnection means a feeling of being emotionally and physically isolated or alienated from significant people and/or one's community.

Sibongile's story indicates that the impact of her mother's death has, for her, somehow created a certain level of disconnection from significant people in her life. She seems to feel that there is some separation between her and people like her extended family, her sisters and her community. She described the situation as follows:

My mother has three siblings; and her younger sister that I call "aunty" was the only one supporting us. The others were not supportive. They were just folding their hands and waiting to see or hear what is happening so that they can gossip about it. Even on the day of the funeral they were sitting in our bedroom, in my home, gossiping. I don't think they are really interested in our lives but they just want to hear what the latest is. That hurt me a lot because they don't care about their family. I don't even know why they came because all of them were not really in good

speaking terms from a long time ago. So they did not really keep contact with each other. They only came for the funeral and they did not really contribute much to help us with burial.

Sibongile described how her family has been disconnected and isolated from each other from a long time ago. She believes that this has affected their support and care for each other in a negative way. She said the lack of contact and communication between the family members throughout the years created the initial distance and disconnection. She said that sometimes she worries about the disconnection she perceives in the relationship between her sisters and her extended family. She was particularly worried that they were not close with the rest of the family. She believes that there is a need for families to be close together because they might need each other someday. One of the concerns she raised was that there might be no elderly person from her family when the need for such a person to represent the family arises or even to help them oversee important matters of the family. She mentioned that she still needed support and advice from significant people, especially her family because it helps her to stay connected to their traditional beliefs. In the story she said:

Sometimes I worry a lot about the way we are with the rest of our family, because if one of us has to get married there will be no one, no uncle or no elders to take the responsibility of arranging and taking lobola for us. I don't know who will be there for us and that is my fear. Even if we are grown-ups now, we still need elders to be there because they know best how to do these traditional things.

The other isolation and a sense of disconnection identified in Sibongile's story is between her and her sisters. The disconnection

became more visible when Sibongile decided to move out of the main family home to one of the shacks in the yard right after the death of their mother. Sibongile and her older sister were physically and emotionally distant from each other for a long time. It became clearer when her older sister decided to leave them in order to live with her boyfriend, knowing that her mother was a sickly person and that they were struggling to meet their needs. She said that throughout her mother's deteriorating illness, her sister was not present to help them or even to call in order to find out how they were coping. She described their relationship as filled with constant conflict that appears to be fuelled by anger and resentment emanating from their unresolved issues. It seems Sibongile is still harbouring feelings of anger towards her sister's actions because she still does not understand why her sister abandoned them when they needed her support. To aggravate the situation, she does not appear regretful for doing that. Her expression was:

It was painful because we were so young and we were alone most of the time. I mean Lindiwe left us. She left us in 1996 to stay in Alexandra with her boyfriend. It was like she didn't want anything to do with us anymore because she never came home and she never called to hear how we are doing. We were the ones calling her all the time until we also stopped calling her because it was like we were bothering her. I did not understand why she was doing that because she knew that Mama was not ok. I mean she was sick for almost two years before she died, and that never told her to come home to see her, wherever she was. I don't understand why.

Sibongile sounded angry at her elder sister for creating conflict and separation between them (sisters), because she feels that she cannot

be close to her younger sister anymore. It appears that she blames her for the distance and disconnection between them:

Things started being sour between me and my older sister. All of a sudden she wanted to control us but she was not around for all this time. And I just stopped talking to her. I moved to one of the shacks outside with my son. I don't have to listen to her and she can be a cruel person too. It is bad because now I can't even talk freely to Linda, we are not that close anymore because of Thandeka.

She believes that if her mother was present she would make sure that they got along, because she would address the differences that they were failing to deal with. She expressed her pain this way:

For all of us at home, we need our mother because we are not getting along and our life is not going good. We need an elder because if Mama was still alive, things that are happening in the house would not happen. She won't allow us to live together without speaking to each other.

She thinks that they still need their mother to help them resolve the conflicts. It seems that even though she does not like how her older sister treated them, she still believes that they need each other and should try to reconcile.

It appears that Sibongile's sense of isolation and disconnection from significant people started from the time her mother became seriously sick, and she had to be home on a full time basis in order to take care of her mother. That meant that she had to leave school as she was the

only one who could take care of her mother on a regular basis. Since then, she has not returned to complete school. It appears that she became isolated and somehow disconnected from school, friends and community. Suddenly her own life had to take a different direction she did not anticipate.

Sibongile seems to be lonely and isolated from her entire family. It appears that the only sense of emotional connection she has is with her boyfriend. Her moving out of the house seems to have created more distance from significant people in her life. It also appears that the kind of life her mother created around them has also greatly contributed to their sense of isolation with family and the community. She was not in good speaking terms with her own siblings and she also avoided making close relations with her community members. This appears to have created a sense of disconnection with others. She expressed the difficulty, pain and loneliness she experienced throughout that time and believed that the presence of her mother would have made a significant difference during that time. The issues of stigmatisation and discrimination often go hand in hand with HIV/AIDS, and those affected and infected are challenged everyday. The following theme shows how Sibongile was challenged throughout her life.

4.2.2.3.5 Stigmatisation and discrimination

HIV/AIDS has been recognized worldwide as a stigmatized disease that is rapidly claiming the lives of many people worldwide (UNAIDS, 2007). Many people still struggle to be open about their life experiences with HIV/AIDS, because of fear of rejection and discrimination, fuelled by this stigma. Disclosing one's HIV-positive status has become an

overwhelming act to undertake. This is mainly because doing so can create many challenges that one would have to deal with.

Sibongile's story reveals the challenges that individuals affected and infected by HIV/AIDS face with regard to issues of stigmatisation and disclosure. She talks about how her mother and aunt were unable to disclose her mother's HIV positive status even when she was extremely sick. This was despite the fact that she was the one nursing her the whole time. This is what she said in this regard:

She was sick for a long time, for two years; but she started showing that she was really sick in 1998. But still she did not tell us what was wrong with her and we did not ask her because of respect for her as our mother. So I did not ask her what was wrong. If she did not say anything as our mother how can we ask. Maybe she saw us as children, maybe that's why she did not tell us then, but I don't know why. Most of the time she talked to my aunt, so I thought that it was not our business so just leave it as it is and hope that they will tell us at the right time. It was the same day when Mama was really sick, and my aunt told us that at the clinic, they made some tests and said that she has AIDS. She said that we should not talk about it as long as we know what is wrong with her and how we can help her. But she never said anything to us and she never talked about her health, she died with it.

She said that she nursed her mother for a period of over two years but no one could tell her that her mother was ill from HIV. Sibongile thinks that her mother did not want her to know that she was HIV positive. It appears that the family was also not ready to disclose the status of their own family member; and wanted to avoid talking about HIV/AIDS

as much as possible. Even after they disclosed to Sibongile and her sisters, Sibongile's aunt asked them not to talk about it again, not even to their mother, as long as they know and understand why their mother was sick.

She thought that her family's intention was to protect them from being stigmatised and feeling isolated and discriminated against in their community. Although Sibongile believed that her family was genuinely concerned about them, that they did not want them to be too worried about their mother all the time and to be reassured that as elders they have everything under control. She also believes that their reasons were out of fear of stigma and rejection from their community. She believes that they were afraid of being isolated, and that they might not get help or support when they need it.

It appears that her mother had already isolated and distanced herself from the community to avoid feeling stigmatised or even having to explain to people what was wrong with her. She said her mother was also a person who did not have many friends. As a result of this she did not have many people coming to visit her when she was really sick. She kept to herself and did not really go out to visit other people either. Sibongile also feared that people might not want to be near her mother or be associated with her in any way once they knew her status. She recalled an incident where a certain lady in their neighbourhood used to gossip about her mother, specifically that she had HIV. She remembered how much that experience hurt her. On this score, she said:

I think it was out of fear that people will start to gossip about her and maybe push her aside rather than help her. You know maybe people will not want to be near her. I know that people

will just gossip and not help. I know why she did not talk about it because there is a certain woman, she is one of our neighbours and she was going around talking about our mother. I heard that she told people that Thoko, my mother, has AIDS. That was before my aunt told us the truth so somehow I suspected that it was it. When I heard the gossips I used to get really angry and hurt to see that people can be mean and can really hurt you. So I just stopped talking to that woman till today. I mean how can a person gossip about someone who is really sick, instead of helping you go around talking horrible stuff. It's not ok because it's painful.

Because of the negative stigma attached to HIV-positive people she was made to feel like something with her mother was wrong and unacceptable. That experience made her realise how difficult it is to disclose one's status and then be unfairly judged. She saw how people could distance themselves from HIV-positive people by gossiping rather than lending them a helping hand. Although Sibongile knew that people could be mean and uncaring towards people who are HIV positive, she was hurt and angry. She also decided to distance herself from the issue and from such individuals by not talking to them anymore. Instead, she decided to focus on matters relating to her mother's welfare on her own. She also avoided the issue by not confronting her mother about the stories she heard. In her explanation she said that it was not important for her to know about her mother's status. She realised that the important thing for her was to treat her mother the way she had been treating her even before she knew about the existence of HIV.

She expressed this viewpoint thus:

I wanted to treat her like my mother all the time and not to see her as AIDS because that is what I think she wanted by not telling us. Because I could see with myself that sometimes I felt really sad and scared that she will leave us, so by not talking about it helped us to not think about it, about her dying. Even though I knew and I think she also knew that it was wrong not to tell us, somehow it made it easier for us not to be too scared of the whole situation. Maybe we might be too scared and too worried over small things and I think by not telling us, she wanted us not to worry too much about certain things and to make us feel that everything is fine.

Her experience shows that there is continues to be discomfort and a lack of openness about HIV/AIDS among some HIV-positive people. The instance of silence in Sibongile's family appears to be fuelled by discomfort emanating from the fear of stigma and rejection. Sibongile states that her reason for not wanting to talk about HIV with her mother was mainly influenced by the fear of death that she might have to deal with one day. She felt a sense of discomfort when she thought about her mother's death. By not talking about her illness helped her not to be preoccupied with death or about every small thing concerning her mother's health. She thought that it served to protect her from being too worried about her mother in order to concentrate on other things. Although Sibongile felt fearful and scared to talk about HIV, she believed that it was wrong for them to avoid talking about the situation they were in anyway.

Sibongile's fear of confronting the truth is also reflected in her own life when asked about her own HIV status. This is clear from the following extract from her interview:

R: *What happened to the father of your child? How did you cope with his death?*

S: *He fell sick for a short period. He told me when he was sick that he has TB from HIV. Not so long after that he passed away. He just became really sick for a few months and then he died. It was the same year Mama died, Mama died in August and he died in February.*

R: *How did you feel knowing that your boyfriend was suffering from HIV?*

S: *It was hurting then, but I went for TB tests at the clinic and they told me that I was fine.*

R: *Have you been for HIV testing?*

S: *No*

R: *How come?*

S: *I am not sure why but I think its fear but I will go soon. Eventually.*

R: *What do you think the fear is about?*

S: *I don't know, I will go. I think its fear of knowing the truth and how I will cope with it.*

R: *What do you suspect the truth is?*

S: *I am not sure and I don't think I am ready to know yet but I know it is important for me to know my status. So I will go eventually.*

R: *Do you suspect that you are HIV positive?*

S: *I think so but I wish I am not, so I will wait for the results rather than assume.*

At the time I asked her about her status, she appeared really uncomfortable and wanted to cut the conversation short. She gave short answers without much detail. Just like her mother and her aunt, she wanted to quickly avoid the topic. It appears that the conduct in her family, especially her mother and aunt, of not confronting the truth and dealing with it, influenced Sibongile. However, she did not go for HIV testing especially knowing that her boyfriend died from an HIV-related illness. She said that she was not sure why she did not go for HIV testing, but suspected that it was the fear of knowing the truth and how to cope with it. It seems she knows what her status might be, but it is confirming it that seems to be a difficult experience to contend with. In the interview she wondered whether she was ready to deal with, or hear the truth. She was sceptical about her ability to cope with it.

This shows how Sibongile was, directly or indirectly, influenced to perceive HIV/AIDS: by keeping quiet and dying with it. Like her family, Sibongile has succumbed to fear rather than confronting the truth. Like her mother, she opted to distance herself from the situation by not confronting the truth and letting fear override the reality of the situation. The experience she went through in respect of her mother's illness has fuelled some of the misconceptions she has. For instance, that not confronting or talking about HIV/AIDS helps a person to cope with the situation as one is not constantly reminded of it and therefore does not have to deal with it. It helps the person not to be too preoccupied and concerned about death or other issues related to HIV/AIDS, such as having to disclose and being stigmatised.

Sibongile is now in another relationship and said that, at times, she had not used protection during sexual intercourse. This, obviously, puts both of them at risk. Sibongile's experience shows how the stigma associated with HIV/AIDS can have such a great influence on people's perception and action. Her childhood experience taught her that HIV/AIDS is unacceptable and should be feared. It should be kept a secret from others and be avoided so as to keep it out of sight or mind and not deal with it. Now that lesson seems to be costing her a life that can be cut short unnecessarily. She grew up with the fear of HIV/AIDS that she feels dissuaded from taking action that can protect and save her life. The impact of the whole experience has made her avoid confronting the situation. It seems it has also left her feeling isolated and disconnected from her community and family. There are many challenges that Sibongile faced at a young age; and now that she has grown to be a young woman it becomes interesting to see how she thinks all this experience has done to her persona.

4.2.2.3.6 Ego Identity

Through the journey to discover her self identity amidst all her life challenges, Sibongile recounts how she thinks and feels about herself. In her story, Sibongile states how unhappy she feels about herself and even fears that she might still amount to nothing as she sees no significant change in her life. She said that she was not happy about herself, and further describes herself as an insecure person, who feels both unsure and fearful about her future.

I think I am a sensitive person. I get hurt or offended easily. Like I worry too much about what other people think and I always think about what they will say or think when I have to make decisions. I am not really happy about myself because I fear

being on my own and trying things on my own because I am insecure about my future and about myself.

I think if you can do things for yourself you can be confident of yourself, so I want to be confident and independent.

Sibongile affirms that her sense of insecurity has made her become sensitive about other people's perception of her. She believes that some of her decisions are likely to be influenced by other people's perception. It seems that she has a need for validation and reassurance in order to feel secure enough to explore things. She also adds that her level of dependency on others has also played a major role in her life because she not only needed financial and material support but also emotional support, and reassurance of a parent.

She seems to believe that if she is independent she can be able to feel confident and secure about herself. But being too dependent makes her feel insecure, uncertain and fearful of the outcome of her future. She seems to believe that she has not developed into the person she desired to be hence she is still afraid that she might not be able to amount to anything significant. This explains her continued sense of dependency and insecurity.

I depend on other people and that is what I am worried about, that I will just be no one with nothing, nothing to give to my child. I want to be happy and I think if I am independent I can be happy and confident. I want to look for a job once I am able to take my child to day-care, find a way to finish my matric. At least I can be independent and happy.

Her thoughts suggest that she does not perceive herself as a productive member in her family, and has not really occupied a stable, suitable and meaningful role and identity as an adult. The implication is that for her being unable to be self dependent has not allowed her to find a suitable role and identity in her environment. She believes that the discontentment about herself image is mainly influenced by the loss of her parent; someone who had given her support and encouragement. She believes that her mother would have not only given her financial and material support, but also emotional support to develop into a secure person she wants to be. She believes that had her mother been alive she might not have been compelled to take certain decisions she has taken in her life. She has a strong view that not having appropriate parental care and support somehow contributed to fears and uncertainties about her future because she had to worry about providing basic things for herself, rather than focus on school and education. This is reflected in the following remarks:

They (parents) somehow take worries about certain things away because they make it easier for you to focus on school and your future and they focus on providing the things you need.

She strongly believes that she missed her teenage hood because she became preoccupied with the need to survive in the situation she was in at home. Her mother might have helped to alleviate certain fears about herself because of the warm, caring and encouraging relationship they had. Her desire to have motherly support and advice, for her, means she will have someone warning her, supporting or guiding her through life. Having a parent can be beneficial because parents generally have life experiences that they can share with you in order to help alleviate certain fears about life. She cites the example of when she was pregnant and needed someone to be with her through

that process. She said she has fears of even being on her own and trying new things because she doubts herself. She seems to have poor insight into her potential and abilities because she feels that she has not really explored and discovered what she is capable of doing. And because of that she fears being alone and losing the people that she loves as that would possibly make her more vulnerable. Her impression is captured thus:

I am not really happy about myself because I have fears of being on my own and trying things on my own because I am insecure about my future and myself. I also have fears of losing the people that I love and being alone and lonely. Right now, I feel like I am alone already and it makes me feel insecure.

Sibongile's story reflects her struggle with low self esteem and poor self image. She believes that the only way of overcoming this situation is to find a job so that she can be self dependent. She seems to feel that she is not a productive member in her family and community because she is more dependent on others for her survival. There is a strong sense of guilt on her part that she is not providing for herself and her son the way she wants to. This makes her feel that she has not explored what she is capable of and develop it as part of her identity development.

It appears that she is still searching for her true potential, and the ability to commit to a certain identity or role, both in her family and the community. Sibongile seems to blame her situation on the fact that she was orphaned as a teenager, and thus had lost the support and reassurance essential during that stage of growth. She felt left alone and uncertain about her future. She also fears that she is in the wrong path of her life. She believes that the early death of her mother to AIDS

has thrust her deep into more financial difficulties with lack of proper emotional support. She believes that most of her unfortunate circumstances and decisions were highly influenced by this reality.

4.2.3 The story of Rethabile

4.2.3.1 Biographical Information

Age: 21 Years Old

Gender: Female

Level of Education: Grade 10

4.2.3.2 Family background

Rathabile is a 21-year-old girl from Tembisa. She is in grade 10. She has an older sister, Maggie who is 24 years old and younger brother, Ramodiegi, who is 19 years old. She lost both parents to HIV-related illnesses in 1997. Her mother died in May 1997; followed by her father in October the same year. According to Sibongile, their extended family no longer wanted to support them after the death of her mother because she had been HIV positive when she died. When her extended family realised that her father was also becoming increasingly weak from HIV, they left them to struggle on their own.

Rethabile and her younger brother were left to care and provide for themselves and their father. She could not go to school anymore because she was told by her uncle and his wife that she must look after her father because no one would. They were then removed from the main house to a shack outside because they were complaining that her father had an unpleasant smell that made the whole house to have an odour. They were neglected. The family did not even come to check on their father. She had to bath and feed him until he died. She watched as her father's health deteriorated until he eventually died.

Rethabile was unable to complete her high school education because she had to nurse her father after her mother's death. Eventually her younger brother was also taken out of school because he was told that their parents did not leave any money for them, and therefore he had to help around the house. Her older sister was also unable to help as much as she could because she was working away from home and had to provide for them. Consequently, Rethabile became the maid at home, while her younger brother ran errands for others. Their cousins were allowed to go to school while they remained at home doing house chores. Rethabile said that they were made to feel guilty for not having parents to take care of them. As a result, she decided to be a hard worker at home so that they would appreciate her efforts and contribution. She wanted to win their love. After a while, her uncle and aunt realised that she was a hard worker and they then decided to send her to a family friend to work as a maid. During that time she was told to bring money home in order to help them because they were their guardians. She worked there for a year until her other aunt decided to take her.

Rethabile felt that their life became easier when their aunt (her mother's older sister) came to fetch them so that they could live with her. Although they were left behind in terms of school, she said she felt happier there. There were many issues and challenges that Rethabile went through as a child and some of them will be discussed in the next section (psycho-social issues).

4.2.3.3 Psychosocial Issues

4.2.3.3.1 Education and outlook on the future

The death of her parents resulted in Rethabile having to contend with losing many important things in her life. She forfeited her parent's inheritance and was deprived of financial support to secure her future. Throughout the interview she emphasised how much she missed feeling safe and secure because her father used to make her feel confident and secure. According to Rethabile, he was able to provide for most of their needs. However, that fell apart when he started losing his health to AIDS. It appears that Rethabile and her siblings lost their inheritance or anything that belonged to their parents due to a lack of support. They lost everything to their uncle and aunt who did not really care about them. When their parents died all the comfort and security they were giving to their children disappeared. They were left with people who did not have their best interest at heart.

Rethabile said that her parents were loving people who cared and were thoughtful of others. She described her mother as a nurturing person, who was always interested in their school education and progress in life. She wanted to know everything they were going through, especially about their school experience. She saw her father as the provider, who had worked hard in order to make sure that his family had everything that it needed. As a child they made her feel that her life and future were safe. She said:

My parents were loving people who liked doing things for other people. Even though we were too many in the house, they sacrificed a lot of things that they wanted for themselves in order to provide for the whole family. My mother was always aware of our needs and made sure that they were met; especially anything that had to do with school. She made sure that school came first because she wanted us not to be like her.

I miss knowing that she was always there to make sure that we did not lack anything. She always made things seem like they were not that much of a problem even if they were because she will just say don't worry about it. I will deal with it. She made me feel that if I am in trouble she will be there to handle it. I miss that security and assurance that she gave me, unlike now I have to be thoughtful of my aunt. We used to come first in their lives but now we have to consider other people.

Rethabile emphasised how she loved the way her parents were involved in their lives. She felt that her mother knew everything that was going on in her life, especially at school. She attended school meetings and tried to get everything that they wanted or needed. She said her mother wanted them to have education so that they could have a better future and not end up like her. If there was something she could not do for them, she explained why they could not get it then, and she would make an effort to get it. But then all this changed when she started being sick.

Suddenly there was no one to take care of school necessities as their father was also away due to work commitments. Then it became the same story again when her father also became sick. Her childhood and the opportunity to go to school were traded with a traumatic process of taking care of her dying father. Rethabile spoke with sadness and disappointment that even after the death of her father she was still not allowed to go to school because she was told that her parents did not leave them money. She said:

No one said anything about school, but my cousins were going to school. When we asked they said that there is no

money to take all of us to school and that our parents did not leave any money for us.

Rethabile felt devastated that she was not going back to school. She thought that going back to school would help her forget about the problems at home, and cope with the loss of her parents. Being at school and away from home would help keep her mind off many unpleasant things happening in her life. She wanted a sense of continuity, a feeling of moving forward and something that would help her to cope with her loss.

Rethabile still feels that her circumstances continue to deprive her of the opportunity to progress educationally, because her aunt is unable to provide them with further education. She feels that they are just too many for her. She believes that they can only make it if some of them got bursaries. Rethabile believes that her parents would have done their best to provide for their education; but now she has to be dependent on someone else and has to accept what they give her. She concludes by saying, *“So losing my parents will always affect my life, it is something I cannot change and it is something that will always influence my life”*.

Rethabile feels that the deaths of her parents to AIDS will always influence her life because they took with them everything that she needed as a child. She stressed that she still needed parental love, care and support. She complained that she missed her parents' love.

4.2.3.3.2 Parental love and care

As a child who lost both parents at a young age, Rethabile emphasised how much she particularly missed her parents' love, care and support.

Throughout the interview she spoke of how she used to feel rejected and isolated by her extended family. She tried buying their love by being a hard worker and being “the best” at doing things in the house. She became desperate and fearful that she might be on her own just like the time she was left on her own to take care of her father at a young age. Her uncle and his wife made it clear that they did not really care about her, her needs or education. They did not show her love and appreciation, despite the efforts and contribution she made at home. Rethabile described how difficult it was to live in that house because she felt unwanted and uncared for. She felt more pain and disappointment at the thought that her father used to take care of all of them without discriminating against anyone for anything.

She said that everything started to change for the worse when her mother’s health started to deteriorate. She described that period as the most difficult time of her life, especially the thought that she might lose her mother. She felt that there was a sense of hopelessness among people and her family. She noticed that her family and friends were really coming to say “goodbye” rather than encourage her mother to recover. That made her angry and sad. It was difficult for her to accept the fact that her mother was dying. As a result, she held on to the hope that she would not die even though she saw how weak she was. This is what she said:

It was very painful for me because no one can replace my mother. I loved her and she loved all of us. It’s painful to lose a mother.

Rethabile felt that as a young girl, there were other things that she felt she needed from her mother. In this regard, she said:

As a girl I needed support from my parents especially my mother. I miss her love, her efforts in making us happy and the time she had for us. And even a small thing like doing homework was not easy, because there was really no one helping us a lot. It was difficult because other children had people helping them at home. I also remember the time I started my menstruation periods, I was shocked and worried that I was sick. I didn't understand what was happening to me. I didn't even know who to go to.

And if she was still here with me she would have prepared me for such things (crying). It would be good and nice to know that I could always go to her for advice.

Rethabile felt that she was deprived of having a good and supportive relationship with her mother. This was worsened by the fact that she did not have any close relationship with anyone in the family. She described how this became even more frightening when her father was now becoming sick and weak. She said that she felt more scared and cried a lot because she could not understand and accept what was going on in her life. Out of frustration and anger, she questioned God for taking away the most important people in her life. She blamed herself, and really wanted to know what is it that she had done to deserve that and how she could correct it.

When her father became bed-ridden, her uncle and his wife started to treat them harshly, and made them feel unwelcome. Sadly this happened when they needed them the most, and when they needed their love and support. On the contrary, they rejected and isolated them.

Losing her mother and father took away that sense of security both emotionally and financially and only brought uncertainty and despair in her life. She lacked a proper support structure that would give her reassurance and encouragement. She described her mother as a person who had always been aware of their needs and made sure that they were taken care of. She saw her as someone who was always aware of what they were going through because she took interest in their lives. She said her parents had always given them the reassurance that everything was, and would, be taken care of.

Rethabile believes that the actions of her aunt and uncle after the death of her parents were “cruel and mean”. She felt that life became better when she was taken in by her aunt from her mother’s side. Notwithstanding this, when asked about what she missed the most about her parents, she said:

I miss their love for me, for us as their children. Our parents really showed us love and took care of us the best way that they can and that’s what I miss the most.

She added that having parents who loved and cared about her was still important for her. Like every child, she felt that she needed parents who were concerned about her future, especially about her well being. She believes she was deprived of that when her parents died early in their lives. She feels insecure and unsure about the future and about herself. She strongly felt that there are many uncertainties about her life. This was further aggravated by the feeling of isolation. Rethabile lamented the fact that she felt isolated and disconnected from her family and community, and further that there was no support given to her.

4.2.3.3.3 Isolation and a sense of disconnection

The theme of rejection and isolation has been identified as significant because it appears to have had a remarkable influence on Rethabile's life.

In this context, rejection and isolation refer to feelings of alienation and isolation by significant people in one's life. This occurs when a person feels unloved, and making him/her feel intentionally distanced and disconnected, emotionally and/or physically. She felt that they were stigmatised and discriminated against because their parents had AIDS. Rethabile felt that her extended family rejected and isolated them when both of her parents died from AIDS. She said:

Things started to change in the house. It was not a happy time in my life because my family started treating us bad. My uncle and his wife started treating us like we did not belong there anymore.

She described her experience during that time as painful because she watched as her family gradually changed to be cruel and mean towards her family. She did not believe that it was the same people whom her father took care of when he was still doing well. She felt that they intentionally rejected and isolated them, because they were afraid of AIDS and therefore did not want to be associated with it. She further suspected that they were concerned that people in the community would also think that they also had it. She described the isolation and disconnection that her parents were subjected to when their health started to deteriorate.

She recalls how her mother was left alone most of the time when she was sick. She said that she was only talked to when food was brought to her, and that she was even excited every time Rethabile and her

younger brother came back from school. She was not properly taken care of and was avoided most of the time because they were scared of AIDS. She believes that even people who came to visit her were mainly interested in seeing a person who has AIDS not necessarily out of concern for her mother. She said:

I can see why people came to see my mother when she was sick because she looked like a different person. She was thin and dark than how we are used to seeing her. She did not look good. So that's when I could understand why people were so scared of this AIDS.

After her mother's death it happened again with her father. This time it was worse because her family made it clear that they were not welcome in the house anymore. Her family's cruelty to one of their own became clear when they asked Rethabile to move out with her father to one of the shacks outside because they were not comfortable having him in the main house.

They left Rethabile and his younger brother to be the ones taking care of their father. They also had to feed to bath him. They were not helped with any responsibility pertaining to their father and, in addition, they were expected to continue doing their chores of cleaning and cooking in the main house. They were left to witness their father's health and life deteriorate in front of them without showing any sense of pity or guilt. She believes that her family were ashamed of her parents and did not want to be associated with AIDS or anyone with it. This explains why they isolated them from the rest of the family. It seems that they did not want people to think that everyone in their house had AIDS. The pain and humiliation she felt is clearly captured thus:

I think I understand why my family wanted us to live in the shack outside. It was because my father had AIDS, and nothing else. They just did not want to be near anyone with AIDS. It was very painful to see people who are your family rejecting you, it was very painful. I had to see how my family became so cruel to Papa because of having AIDS.

At a tender age of 11, Rethabile was thrown into the responsibility of nursing her father, who was already on his death bed. She talked with sadness and pain when she described all the things she had to do for her father because no one else wanted to do them. Rethabile witnessed as her parent's health deteriorate and eventually die. Without knowing what is going on and without receiving significant support from those who are supposed to care about her, her life was already clouded by lack of love and poor support structure, rejection and isolation by significant people in her life. She suffered rejection and abuse as a child. She was robbed of her childhood and even everything that was owned by her parents was taken from them because her parents' early death to AIDS, as well as a lack of openness about HIV/AIDS, deprived them of the opportunity to plan properly for their children. The early death of her parents to AIDS turned her life in a challenging direction. To Rethabile and her brother, that experience not only stripped them of their inheritance, it took their sense of belonging and connection to a larger family.

The abuse and disconnection she felt was also seen when her uncle and his wife decided to make her work as a maid and being told to support the family financially. She was taken out of school and was deprived of the opportunity to go to school. It became clear to her that her extended family was not interested in caring for her in any way.

That decision confirmed and symbolised the emotional and physical disconnection and isolation by her family. Rethabile believes that they were mean to her because her father was no longer helping them with money and he was too weak to question things in the house. She believes that they used her father then, and now that he was gone they were using her. Her suspicion is captured thus: *"They used Papa and now they are using me because Papa no longer brought money home"*.

She seems to believe that her extended family did not feel the need to worry about taking care of them because their father was not giving them money anymore. Her pain and sadness appear to be aggravated by the thought that her parents used to give everything they had in the house and for the whole family, but they were unable to take care of them. They instead cut them off emotionally and physically by treating them like maids in their own home, while their cousins went to school and enjoyed their childhood.

She describes that experience with pain and sadness, and she said:

The whole time I was the one cleaning the house and cooking, even the main house because I was no longer going to school. That became my job. We were given food and we could not touch anything that was not given to us. It was painful to live in that house and knowing that there is no way out.

The rejection, isolation and lack of empathy by Rethabile's family towards them became evident. She had to endure the pain of losing both parents to AIDS, as well as endure pain of being rejected and alienated by those whom she considered to be her loved ones.

Throughout her story she described many things that she wished to have as a child. Key to these was parental love and care. The feelings of rejection, isolation and disconnection from her own family made her realise how much she missed and needed her parents. Although she was young, the experience she went through did not spare her any pity. Like many children affected or infected by HIV/AIDS she had experiences that made her feel stigmatised and discriminated against. This will be discussed in the next section.

4.2.3.3.4 Stigmatisation and discrimination

At a young age Rethabile had to contend with rejection and isolation due to the stigma attached to her parents when they became sick with AIDS. This theme highlights the circumstances that many children like Rethabile have to deal with because they are simply associated with HIV-positive individuals.

From the onset Rethabile openly spoke about how her extended family treated her parents when they were sick. She said it all started with her aunt who told people that her mother was sick from AIDS, and people came merely to see a person with AIDS. She could not understand why so many people came to see her mother, but now that she knows about HIV/AIDS she understands why. This aspect emerged from the following remarks:

But then as I grew up I knew and I can understand why people came to see my mother when she was really sick, because she looked like a different person. She was thin and dark than how we were used to seeing her. She did not look good. So that's when I could understand why many people were so scared of this AIDS.

However, she felt that it was not a pleasant experience when many people came to see her. Even though she was young, she felt that they were somehow ill-treating her by allowing everyone to see her. She felt that they were not only mocking her, but instead made her health deteriorate even more. In this respect, she said:

There were many visitors who came to visit her as if they were coming to say goodbye, some would cry and I used to get very angry at them that they came to say goodbye so my mother won't even fight to stay alive. I was angry and sad at that time. I asked myself why they lost hope when she was still alive.

Everyone in the house talked as if she was going to die very soon and they talked about the funeral and they talked about money. Everyone lost hope that she was going to recover

She felt that people around her and her mother were not doing much to help her mother. Instead, they were hopeless and helpless. They made her feel even more hopeless and helpless that she did not fight the illness in order to stay alive. Rethabile felt that at that time her mother did not receive enough support and attention. She was just put in her room so that she would not be around them. She recounted how she felt at that time, and said:

Even when I was at school, I was always worried about her. When I left for school in the morning I would really feel like staying with her. I knew that there were people in the house to help her but she looked lonely when we were not there. She would be so happy when we came back from school because at least she would have someone to talk to. They did not talk to her

that much; only when they brought her food or wanted something. So, she was lonely.

Rethabile felt that her mother was isolated from people and the rest of the family. She looked lonely as if she was left to deal with the disease on her own. She felt that they also did not want to be associated with individuals with AIDS, or be seen as supportive towards them; hence, they did not want to get too involved. Rethabile said that their feelings towards the disease became clearer when her father's health started to deteriorate. The family started to really show how uncomfortable they felt about her parent's disease. It appears that it was at this time that the family started to discriminate against them, because of the stigma they attached to AIDS. They had the idea that it was something that was unacceptable to the family; hence they then isolated her parents from the rest of the family. She described with pain and hurt the times that she had to care for her father on her own because her family did not want to. On this point, she said:

And as he got worse I could not go to school anymore because they also said I needed to be home so that I could take care of him, and then I left school. They even moved us out of the main house because they felt that my father made the house smell. They moved him to a shack outside and they said I must stay with him there because I was the one taking care of him. I used to do everything for him because no one would go into his room. I cleaned for him, sometimes I even bathed him and fed him because he would be very weak to do everything by himself. [Crying] It was so painful to see what they were doing to us even before Papa died, and I think that was why he died so quick. I think he lost hope.

It was clear that Rethabile and her father were stigmatised and discriminated against because her father had AIDS. Firstly, she was not allowed to go to school anymore because she had to take care of her father. Secondly, they were both move into a shack outside because they felt that her father had an unpleasant odour that made the house smell. They could not live in the same house with him and wanted nothing to do with him; so they removed him from their sight.

Rethabile still believes that her father also died much quicker during his illness because the people around him were not supportive and caring enough to encourage him to want to live longer. She thinks that her father was very sad at the situation and lost hope. The lack of proper knowledge and the fear of being stigmatised claimed the lives of her parents because it compromised the chance for them to receive better and proper care and support:

I had to see how my family were so cruel to Papa because of having AIDS. I did not understand; but as I grew up and learned more about AIDS, I understood why my family wanted us to live in the shack outside. It was because my father had AIDS and nothing else. They just did not want to be near anyone with AIDS.

In Rethabile's view the family was uncomfortable and unwilling to deal with AIDS and were fearful of being around anyone with AIDS. It also appears that AIDS/HIV was a topic that was avoided and not openly discussed. Rethabile said throughout her parent's illness and suffering no one cared to explain to her why her parents were sick. She thought that it must have been something that was very wrong because she heard it through rumours. She could not understand why it was such a bad thing that no one really spoke openly about it. But as she got older

she understood that it was a cruel disease, but also a disease that was not easy to talk about. She said that although her parents did not disclose their status to her, and her extended family did not tell her what was wrong with her parents, she was still punished for being associated with it.

Rethabile's experience highlights one of the underlying issues of HIV/AIDS, which is a lack of disclosure. Her story indicates the impact of a lack of disclosure and openness about HIV/AIDS on individuals infected and affected. It also indicates that many people like her parents have died, or are likely to have their health care provision and support compromised because those around them have fear or do not want to be associated with them. In addition, her experience reflects the possibility that many children like her suffer all kinds of punishment or abuse before and after the death of their parents as a result of the stigma attached to their parents' health status.

They are likely to be left behind to deal with what their parents left behind. For children in Rethabile's situation, this amounts to a legacy of shame. It took away the respect and dignity of her parents from the rest of the family. For Rethabile, the experience took away her parents, their support and love towards her. The section that follows deals with Rethabile's reflection on how she believes her experience played a role in how she sees and defines herself today. The theme "Ego Identity" explores how the participants define their identity amidst the challenges they went through.

4.2.3.3.5 Ego Identity

The theme of ego identity versus role confusion is discussed in order to continue drawing a deeper understanding and meaning of the impact of HIV/AIDS on children/teenagers like Rethabile. As a young girl,

Rethabile lost both parents to AIDS and was thrust into difficult challenges that affected and influenced her self perception. According to Erikson, individuals have a need to develop a sense of identity that reflects their inherent and desired potential or abilities. They have a desire to have an ideal place in society where they are able to fulfil expectations placed on them by their society. Individuals seek to find congruence between their self-image and the role they are expected to fill in their society (Meyer, 1989).

This he refers to as ego identity, a stable and coherent self perception and individuality (Engler, 1989). It is a process that adolescents go through in order to be able to answer the question, "Who am I" satisfactorily, once they have entered the stage of adulthood. Ego identity is described as a person's perception of his or her true self. It is a process seen to be influenced by one's inherent desire and need to develop his or her identity in order to acquire a stable sense of self and role in his or her society. It is one's ability to develop a stable sense of self, it entails certainty about one's own self image and capacity for loyalty towards one's social role in the community (Meyer, 1989).

The process of identity development is said to be influenced by the support from one's significant others such as family or community (Engler, 1989). The support, reassurance and encouragement from significant others like parents, family and community is indicated as playing a significant role in the development of identity. In contrast to "ego identity" is "role confusion", which Erikson refers to as the difficulty of acquiring and committing to a stable sense of identity or self and role as a person in one's community or family (Meyer, 1989). He says it is the inability to conceive of oneself as a productive member of society. He further says that role confusion can arise out of the individual's difficulty finding a meaningful adult role and a

meaningful place in one's society. In Erikson's view, if they fail to do so they will experience role confusion.

Rethabile's life journey reflects how she endeavours to define herself as she changes from being a teenager to being a young adult. The theme highlights the impact of her experience towards the development of her identity. It shows how Rethabile has come to define herself with regard to her childhood challenges. She lost both parents to AIDS at the age of 11 years. She lacked proper parental support, love and care. She experienced emotional and physical abuse and was neglected by people she had considered to be her relatives. She was plunged into responsibilities she was not ready to carry out. Her childhood was filled with sadness, disappointment and hurt. Attending school was her only hope. It was also the only place to explore and identify her potential. This opportunity was also snatched from her without any reasonable explanation. Throughout the interview she expressed feelings of doubt and fear about the future. She felt unsure about her own potential and the opportunity to explore various possibilities. She believes that her experience had an influence on her perspective of things or events in her life. From the onset, she described herself as different from other children but her wish was to be like any other child. The following extract evinces this point:

I did feel different from other children because I was still very young but I was already used to doing things on my own and for myself. I used to work hard to be the best so that my family would not feel like they are wasting time by taking me to school. I work hard on things that I put my mind and my hands on because I don't want to be a failure and I don't want to disappoint my family. My friends at school always said that I like being at home a lot that I never go out to parties or outings

except for school outings. So, that always bored them. They like saying that I am too serious I must relax and be young. So, that made me feel like I was different from other children. I don't remember how to be like a child and relax because I grew up fast when I was a child. I worked when I was still a child and I had responsibilities that were for adults. So, I sometimes forget myself, I tend to become like a mother or some elder to my friends and I think that sometimes irritates them. I was not involved with boys or drinking so they felt like I was trying to be better than them or think that I am different to them. But I knew that I had people who are sacrificing many things to give me a life that my parent cannot give me so I did not want to disappoint them.

Rethabile believes that the circumstances she grew up in will always affect her life. She thinks that her character and attitude have been influenced by her background. She described how she found it difficult to be like her peers because she tends to be motherly towards them. Rethabile believes that having to grow up fast and assume roles with adult responsibilities at a young age stimulated her mothering tendencies. She said she had to care for her father when he was on his death bed, and she was further made to work as a maid at the age of 11. She had not lived her childhood like other children; hence she “does not know how to be a child”. She feels that at times she just wants to feel and be like her peers, be appropriate for her age when she is with them, but still be responsible. She feels that her parenting tendencies make her feel different and pushes her friends away because they get irritated.

Rethabile made reference to certain things about herself that she was not happy with. She mentioned that she feels unable to be herself and

has tendencies of being a people's pleaser because she wants to belong and feel accepted. She wanted to feel loved:

They saw that I was responsible and reliable; but for me it was more of trying to please them so that they can be nice to us and treat us right. And I am still that kind of a person at times. I want to make people close to me happy so that they can like me. Sometimes I don't like doing that because I end up not happy, because maybe I did something that I don't like just to make my brother or a friend happy but it is something that just comes to me and sometimes I regret later.

She believes that she cannot handle her fear of rejection and abandonment. That is why she has become a "people's pleaser". Rethabile believes that this has been a barrier to being who she really is, and who she wants to be. She tends to focus on what other people want, rather than on what she wants, because she does not want to feel like she is pushing them away. She admitted that she had tendencies of not showing her true self, and thus says or does the things that make others pleased with her. In this vein, she said:

But as for myself I am not too happy with some of the things I see about myself. I just want to be myself and stop pleasing people so that they can like me. I want to be myself, I want to be loved for being myself. I want my friends and people that I meet to see who I am; not what they want me to be. I don't want to be afraid of being myself because of being afraid that they will not like me.

It seems she finds it difficult to find a commonality between her real self and the expectation that she thinks others have of her. She

behaves in ways that she thinks others will find acceptable rather than in ways that she believes it represents who she is. It also appears that she has not really explored being herself and seeing how others will react to her. Further, she does not know how she would handle other people's reaction in that regard. She indicated that thinking and behaving this way makes her feel unhappy. She wants to be herself and to be accepted. She expressed herself thus:

And I wish I was more positive about my life and my future because I wish to be better than what I am today. I wish my future was more promising because I don't think any of us will be able to go to tertiary and have degrees. I think we will survive but not to be what we wish to be.

It is evident that her hope of developing into the person she wants to be is greatly influenced by the opportunity to continue with education and finding a decent job. In her opinion, being hopeful means that she can be able to do things that will indicate the kind of person she really is, rather than be something that is more directed by a lack of certain things. It seems she believes that education can be a means to achieving the things that she desires. It will also provide her with resources that will also enhance development or show the kind of person she is. Rethabile feels that self discovery and further development of her identity is possibly compromised because she will not be able to explore other areas about herself such as (i) academic ability and, perhaps, (ii) a certain professional ability because of this lack of educational opportunity.

Rethabile also thinks that the fact that she is raised by other people is another issue that affects her identity development. She believes that being raised by people other than her own parents, with their rules and ways of life, had an impact on the kind of person she is.

She consistently stated that the death of her parents would always affect her identity as a person and as a young adult. She emphasised that parents could have played a major role in her life because they would have made her their priority. She said as a young girl she missed the sense of security and reassurance from parents. She believes that her parents had always given her some sense of security and reassurance because they made sure that they provided for her needs. She feels that her insecurities and uncertainties about the future are largely influenced by the fact that she has no parents to support her through her endeavours. She said:

Losing my parents will always affect my life. It is something I cannot change and it is something that will always influence my life. So, I do think that the death of Mama and Papa will always affect how I see myself. They are not here anymore to help me grow, someone is doing that and that will always be in my head. Maybe, if they were still alive I would be more positive about my life in the next years. I am really not sure what to expect about the future, I can't really plan for after matric, I will just see what will come up for me.

But I miss feeling safe and secure because my father was there and was able to work so that he can do things for us. Our parents really showed us love and took care of us the best way that they can, and that's what I miss the most.

I miss that security and assurance that she [mother] gave me. Unlike now, I have to think for my aunt first before I can do something. We used to be first in their lives but now we have to consider other people first. I miss their love for me, for us as

their children. I miss our togetherness because now we are separated and there is no real connection anymore.

Rethabile feels that she is missing the most important factor in her life. That is, the support, reassurance and security from parents. Being thrown into another family did not necessarily address most of her needs when she grew up. She felt that she was taken care of but she still lacked many important things that she believes she needed. These include education and a daughter-parent relationship. As a child she needed a relationship that can give her love, care, security and reassurance as a young girl, so that she could continue with the business of self discovery and development. Instead, she saw her presence as a financial burden to her aunt and added to the lack that already existed in the household. She had to be thoughtful of her aunt and her family when she needed things. She felt that she could not communicate some of her needs to her aunt because of fear of over-burdening her. It seems some of her needs were compromised or not fulfilled along the way.

4.3 The Researcher's Reflection

This study has been an eye opener and emotionally overwhelming as it raised many contrasting emotions in the researcher. The process of going through the participants' interviews, transcribing their data and eventually analysing and interpreting the emerging themes from their experiences evoked strong emotions in the researcher as she thought about how difficult life must have been for the participants.

However, their stories also raised feelings of admiration on the part of the researcher as she noticed how the participants grew to be strong and courageous individuals amidst the difficult challenges they have

been through in their lives. Their hope and the ability to find meaning to survive each day signify their determination to make the most of their life. Although they still experience many obstacles, they seem able to find ways of coping and redefining themselves.

The researcher also empathized with the participants for all the experiences they were subjected to. She wondered how many children and adolescents were exposed to such trauma and how they found the reason to survive in their environment. She wondered what communities and the country will be like in the next generation, when individuals go through such circumstances at a very young age.

She realised the greater implication of the impact of HIV/AIDS on a larger scale, and the significant need to aggressively deal with HIV/AIDS and its accompanying issues. Accordingly, the participants' stories reflect the silence that buries the process of dealing with HIV/AIDS. The overwhelming impact of their experience also affected the researcher negatively. The thought of how much damage this crisis can have on children and adolescents' self perception became a grave concern.

The researcher was also impressed by the participants' willingness to participate through sharing their experiences, even though this raised many painful and hurtful feelings. The researcher acknowledges their strength and willingness to be open about their private lives, more especially their willingness to talk about the HIV/AIDS status of significant people in their lives. She respects their courage and wishes them the best in their future endeavours.

4.4 Conclusion

This chapter took a look at the participants' stories, as well as the feelings and thoughts that came out of their experiences. It allowed the participants to relive and reflect on what they have been through. The themes, which represented the psycho-social issues identified from each participant, were used to elaborate further on that issue and on how the participants felt. Although the themes were similar for all participants the experiences, including the thoughts and feelings evoked, differed for each participant. It is in this way that the aim of this study, which is to give voice to individuals affected by the impact of HIV/AIDS, could be achieved. Participants shared their own experiences, which were analysed and interpreted individually and not compared with experiences of others in the study.

Different experiences raised different meaning and understanding for each participant. The themes extensively discussed the experience of losing a parent or parents to HIV/AIDS at a young age. They further gave a clear indication that HIV/AIDS can affect different areas of a person's life and those around him/her. The participants spoke about how their experiences played a role in how they perceived themselves, particularly their identities. The results of the study also suggest that one's sense of self or identity can be greatly influenced by their circumstances.

There are many implications arising from the participants' experiences that were identified as highlighting the magnitude of this disease. The

next chapter concludes this study with further discussion of the implications of the research results.

CHAPTER 5: CONCLUSIONS

5.1 INTRODUCTION

This is the concluding chapter to this study. It starts with the presentation of the conclusions made from the overall study. In making the conclusions, the objectives of the study were taken cognisance of. The chapter further looks at the strengths and limitations of the study, as well as make recommendations for future research.

This study identified four main psychosocial issues that are believed to have a significant impact on the participants' lives. These psychosocial issues include the structure of the nuclear family, education, psychological wellbeing and identity formation. In each psychosocial issue there are themes that are used to elaborate further on the respective issue under discussion. These themes are (i) material support and dependency, (ii) education and outlook on the future, (iii) parental love and care, (iv) isolation and disconnection, (v) stigma and discrimination, and lastly (vi) ego identity.

5.2 CONCLUSIONS OF THE PRESENT STUDY

The results of the study show that the participants have a strong belief that the death of their parents to AIDS had a negative impact on their lives. There is a strong consensus between the participants that being an AIDS orphan at a young age significantly challenged their lives at

various levels, including the development of their identity. The following conclusions can be drawn from the study:

Firstly, being AIDS-orphaned creates challenges on various levels, which include:

- Material and financial provision
- Emotional attachment
- Educational opportunities
- Development of identity

These challenges have been seen to influence the participants' process of identity development.

For instance, the impact of HIV/AIDS on the nuclear family has serious implications. When the parents' health starts to deteriorate, the dependent children are plunged into a situation of responsibility, particularly of caring for their ailing parents. In terms of this study, the change in roles was apparent when the parents lost the fight against the disease and died. Their future was threatened because they had to contend with unstable financial and emotional support, as well as continued dependence on others, even in their adult years. Changes in the structure and functioning of the families caused educational and schooling difficulties, a lack of proper financial and material support, poor emotional care, as well as the negative influence of AIDS stigma and discrimination. In short, it has been observed that the impact of AIDS on the structure of the nuclear family had far-reaching implications for the stability at home and the lives of the orphans, as well as uncertainty about their future.

Secondly, the stigma associated with HIV/AIDS deprives orphans of the necessary support that they require. Their experiences show that help seeking behaviour and the need to assist those affected and infected by HIV/AIDS has been negatively affected, and even stifled, by the influence of stigma. The power of stigma seems to push more and more people into their hiding places and perpetuate the stigma (Dane and Levine, 1994). As has been observed in this study, the participants' experience in this regard had a significant influence on their perception about HIV/AIDS in different ways.

Their stories have shown how the existent stigma and discrimination make it difficult for others to disclose their health status. Their reaction towards HIV/AIDS still appears to reflect fear and avoidance of the real issue. It seems easier not to talk about it because one does not have to confront and deal with it. In other words, as Dane and Levine (1994) say, one opts for secrecy and non-disclosure due to the fear of facing other people and their perceptions.

It is clear from the results of this study that the participants required parental love and care. They eventually got disconnected and isolated from their families due to the lack of love and care on the part of these families. They grew up feeling as if they did not belong with their extended families, because these families alienated and rejected them. Some of the participants were even exposed to abuse and exploitation at a young age. They thus felt emotionally abandoned, and neglected by their extended families. In addition to these, the fear and power of stigma created further isolation and disconnection from their own families and communities. This has the effect of hindering support from the same community and extended families, and increased the fear of

disclosure and a lack of openness about HIV/AIDS in the community, and in their lives.

Thirdly, factors that have affected the development of identity amongst the participants in the current study are the lack of parental love and care, as well as financial and material support. As the results have indicated, on different levels and contexts, the participants seemed to feel that the deaths of their parents have somehow deprived them of important things such as love, support, reassurance, security and a sense of belonging. They expressed their need for love and appreciation from their families and significant ones. It would seem that above their need for material things, their greatest need was affection and reassurance from parents or a parental figure.

Lack of financial and material support has been shown to have unfavourable consequences to the development of the participants' identities, because it limited the opportunity to explore and discover who they are in certain areas of their lives. This was pertinent especially when looking at the impact on their education. Thus, education was one of the main psychosocial issues that they emphasised as important, together with getting the financial and material support to achieve it. As soon as their parents became incapacitated by the disease, some of the participants had to abandon school in order to take care of them (the parents). As Foster and Williamson (2000) observe, education often becomes last in the list of priorities once poverty and health care needs increase, and household income decreases. As in this study, many children find it difficult to continue with school or tertiary education because of a lack of financial support and, sometimes, even guardians to help them continue with school and to make sense out of their lives.

For some of the participants, the lack of education, and their sense of hopelessness about the future have put them back into the cycle of poverty and dependency on others; notably boyfriends and even the government for child support grants.

The discussion here suggests that education, which is seen as a tool for survival, seems to negatively affect participants' efforts to build themselves a better future or decent life. Poor and insufficient financial and material support, decrease in household income, as well as the need to care for ailing parents, had a significant influence on the participants' ability to attain education.

It is clear in this study that a number of factors played a role in the development of the participants' identity. A close relationship between parents and children can, for instance, provide the sort of emotional support that foster commitment to an identity (Sculthesis & Blustein, 1994). Such an environment has not been part of the participants' experiences; hence their continued struggle to commit to a particular identity. In addition, the lack of financial and material support has been shown to have unfavourable consequences to the process of identity development on the part of the participants, because it limited the opportunity to explore and discover who they are in certain areas of their lives.

In essence, the increase in child-headed households suggests the absence of parents or parental figures. In such contexts, children are likely to miss out on the quality and contribution of a family relation that is seen as playing a role in the development of identity. The same goes for situations where such children are cared for by extended families. As Campbell, Adams and Dobson (1984) point out, weak affectionate bonds and poor communication levels are thought to

provide an insecure or constricted psychological base for self-exploration and difficulty in defining one's identity.

The participants in this study experienced limited love and care from those in whose care they were left. This led to a situation where they experienced a sense of isolation and disconnection from significant others. Consequently, strong feelings of insecurity on the part of the participants developed. This gravely affected their ability to safely explore their identities.

It is thus concluded that the participants felt that the challenging experiences they were exposed to at their age had a significant influence on their identity or sense of who they are. They believe that their experiences brought many challenges and obstacles that made it difficult for them to explore and achieve most of their goals. Although they rank their needs differently, they believe that the presence of their parents and inherent resources would have made life easier for them. They would have thus had a more secure and reassuring base to explore and discover their abilities and talents if these things were at their disposal.

The participants felt that their environment had certain expectations from them, but provided insufficient support, emotionally and financially, to allow them to explore, discover and define their sense of identity. Erikson (in Engler, 1989) makes the point that once an individual is able to clearly define his/her sense of identity, he/she can achieve the ego strength of trustworthiness or reliability on the self. This means the individual feels secure about himself/herself, and has trust and confidence in his/her ability and potential. The participants did not have this, and they felt that they needed to be in such a situation especially at their current age.

On account of this, the participants experience role confusion, which is a state wherein they have not defined and committed to a certain sense of identity. They all expressed feelings of insecurity and low self-esteem. They do not feel confident about their abilities because they were not provided with the opportunities to fully explore their potential. In addition, their experiences could not offer them the emotional security and support to discover who they are in order to clearly define their identities. It is clear that this discussion addresses the questions that were raised earlier in the study: (i) "Do AIDS orphans experience role confusion?", and (ii) "Do they develop the mature sense of self-identity expected given the environment they grow up in?" The study has shown that they discover their potential in line with how they perceive and define themselves, as well as how others expect them to be.

The conclusions made in this study have thus addressed the main objectives of this study. The study has explored and described the experiences of AIDS orphans. It continued to show that their experiences with HIV/AIDS had an influence on their identity development process. Lastly, the study explored factors that have influenced their identity development.

5.3 IMPLICATIONS OF THE STUDY RESULTS

The results of this study have highlighted the participants' psychological experiences as well as indicate how their experiences affected the development of their identities. The results imply that

care and support for AIDS orphans should be holistic so as to include not only material support but also psychological support.

The second implication of these results relates to the stigma attached to being HIV/AIDS infected and affected. Firstly, HIV care and support programmes need to incorporate the possible damages caused by discrimination especially amongst AIDS orphans. Secondly, HIV prevention programmes need to intensify the fight against the stigma and discrimination associated with HIV/AIDS.

5.4 STRENGTH OF THE STUDY

The study takes into account, the postmodernist view of the existence of a multi-verse of realities. This view takes into account the fact that singular accounts of reality tend to marginalize and reject truths that seem to divert from the set objective truth. Therefore, the study gave a few participants the opportunity to intensely share their experiences, the meaning and interpretation they derived and to reflect on their personal experiences, and thus allow for many realities. In addition, the qualitative aspect of the entire study allowed for multiple realities to be heard, because qualitative studies allow for the expression of participants own realities as well as give voice and depth to experiences.

Apart from giving voice to the participants and their experiences, this study has shed some light into the role of HIV/AIDS on the development of identity amongst AIDS orphans.

5.5 LIMITATIONS OF THE STUDY

In acknowledging the shortcomings of this study, it is indicated that only three participants were used for this study. The study also acknowledges that the participants used in the study are from the same race, neighbourhood and community, and could therefore not be representative of the entire population of AIDS orphans. Although this served the purpose of this study, one has to be cautious when applying the results of this study to the reality of other individuals affected and/or infected by HIV/AIDS. The study would therefore not claim that the findings can be generalized to the entire population of AIDS orphans.

The study also takes into account that the researcher “cannot not” have an impact on the interpretation of the data of the participants. Her values, ideas, and social contexts are reflected throughout the interpretation of the participants’ experiences. The derived themes and understanding given are influenced by the researcher’s presence in the study as she is viewed as a co-writer in the interpretation of new meaning and understanding. However, this was in line with the adopted research method.

5.6 RECOMMENDATIONS FOR FUTURE RESEARCH

The multifaceted impact of HIV/AIDS needs a multidisciplinary and aggressive approach that will foresee that not only physical needs such as shelter, food and clothes are provided for, but also take into account that individuals affected and/or infected need love, affection and acceptance. Therefore, other studies need to focus on how to eliminate or reduce the influence of stigma in order to intensify support for AIDS

orphans. Another recommendation would be to research government and non-governmental programmes aimed at assisting AIDS orphans and those who care for them in our country in order to evaluate their effectiveness in terms of addressing the holistic needs of orphans.

It is recommended that future research should involve a larger sample size, different races, and participants from different neighbourhood and communities, in order to increase the quality of data.

5.7 CONCLUSION

HIV/AIDS is a pandemic that is likely to last for many years to come, and therefore the fight against it will never end any time soon. It will continue to claim the lives of many people (affected and infected) in different ways. It is therefore important for anyone to contribute towards change in whatever way that they can.

The study served its purpose of providing valuable information regarding AIDS orphans and their identity development. The themes generated gave an elaborate understanding and meaning of the experiences that AIDS orphans have. The strengths and limitations of the study were highlighted, and recommendations for future research were also made.

REFERENCES

Addison, R.B. (1992). Grounded hermeneutics research. In B.F. Cabtree, & W.L. Miller (Eds.), *Doing qualitative research* (pp. 110-124). Newbery Park: Sage.

Anastasi, A. (1976). *Psychological testing*. (4th Edition). New York: Mac-Millan.

Ansell, N., & Young, L. (2004). Enabling households to support successful migration of AIDS orphans in Southern Africa. *AIDS Care*, 16(1), 3-10.

Aronson, S. (1995). Five girls in search of a group. A group experience for adolescents of parents with AIDS. *International journal of group psychotherapy*, 45(2), 223-235.

Attig, T. (2002). Complicated grieving and bereavement: Understanding and treating people experiencing loss. In G.R. Cox, R.A. Bendiksen, & R.G. Stevenson (Eds.), *Grieving and Bereavement* (pp 135-139). New York: Oxford University Press.

Akukwe, C. (1999). HIV/AIDS in African Children: A major calamity that deserves urgent global action. *Journal of HIV/AIDS prevention and education for adolescence and children*, 3(3), 5-24.

Barolsky, M. (2003). *Mobile populations and HIV/AIDS in South African Region: A desk review and bibliography on HIV/AIDS and mobile populations*. Geneva: International organization of migration.

Beckwith, B. S. (1980). Identification of spouses and children at high risk during bereavement: A preliminary Assessment of Parkes and Weiss' Risk Index. *The Hospice Journal*, 6(3), 35-46.

Bellamy, C. (2004). *The framework for the protection, care and support of orphans and vulnerable children living in a world with HIV and AIDS*. Johannesburg: Global AIDS Alliance.

Bicego, G., Johnson, K., & Rustein, S. (2003). Dimensions of the emerging orphan crises in Sub-Saharan Africa. *Social science and Medicine*, 56(6), 1235-1247.

Blos, P. (1979). *The adolescent passage*. New York: International Universities Press.

Booyesen, F., & Arntz, T. (2002). Children of the storm: HIV/AIDS and children in South Africa. *Social Dynamics*, 28(1), 170-192.

Booyesen, F.L.R. (2004,a). Social grants as safety net for HIV/AIDS-affected households in South Africa. *Journal of Social Aspects of HIV/AIDS Research Alliance*, 1(1), 45-53.

Booyesen, F.L.R. (2004,b). Relationship between HIV/AIDS, income and expenditure over time in deprived South African households. *AIDS Care*, 16(7), 817-826.

Brink, H.I.L. (1991). Quantitative versus Qualitative Research. *Nursing RSA*, 6(1), 14-18.

Bowlby, J. (1980). *Attachment and Loss*. New York: Basic Books.

Caplan, M.G., & Douglas, V.I. (1969). Incidence of parental loss in children with depressed mood. *Journal of Psychology and Psychiatry*, 10, 225-244.

Campbel, E., Adams, G.R., & Dobson, W.R. (1984). Familial correlates of identity formation in late adolescent: A study of the predictive utility of connectedness and individuality in family relations. *Journal of youth and adolescence*, 13, 481- 509.

Cooper, E. (1989). Caring for children with HIV infection. *Focus*, 4(11), 3-4.

Cooper, C.R., Grotevant, H.D., & Condon, S.M. (1983). Individuality and connectedness in the family as a context for adolescent identity formation and role taking skills. In H.D. Grotevant, & C.R. Cooper (Eds.), *Adolescent development in the family: New directions for child development (pp.43-59)*. Carlifonia, San Francisco: Jossey-Bass.

Crew, M. (2003). *Over Extended: AIDS Review*. Pretoria: University of Pretoria, Center for the study of AIDS.

Cross, C. (2001). Sinking deeper down: HIV/AIDS as an economic shock to rural households. *Society in Transition*, 32(1), 133-147.

Dane, B.O., & Levine, C. (1994). *AIDS and the new orphans: Coping with death*. London: Auburn House.

Denzin, N., & Lincoln, Y.S. (2000). Introduction: The Discipline and Practice of Qualitative Research. In N. Denzine & Y.S. Lincoln (Eds.), *Handbook of Qualitative Research* (2nd Edition) (pp. 1-28). California: Sage.

Department of Health (2006). *HIV and AIDS and STI strategic plan for South Africa, 2007-2011*. Pretoria. Department of Health.

Dickerson, V.C., & Zimmerman, J.L. (1996). Myths, misconceptions, and a word or two about politics. *Journal of Systemic Therapies*, 15(1), 78-88.

Doan, R.E. (1997). Narrative Therapy, Postmodernism, Social Constructionism, and Constructivism: Discussion and distinctions. *Transactional Analysis Journal*, 27(2), 128-133.

Doka, K. J. (1989). *Disenfranchised grief: Recognising hidden sorrow*. Lexington: Lexington Books.

Donahue, J. (2005). *Community based economic support for households affected by HIV/AIDS*. Discussion paper on HIV/AIDS care and support presented at the HIV/AIDS health technical services project. Arlington, VA: Health Technical Services project for USAID.

Engler, B. (1989). *Personality Theories: An Introduction*. Boston: Houghton Mafflin Company.

Erikson, E.H. (1968). *Identity, Youth and Crises*. New York: W.W. Norton & co. Inc.

Erikson, E.H. (1959). The problem of ego identity. *Journal of American Psychoanalytic Association*, 4, 56-121.

Faithful, J. (1979). HIV positive and AIDS infected women: Challenges and difficulties of mothering. *American journal of Orthopsychiatry*, 61, 144-151.

Freeman, M. (2004). Mental impact of HIV/AIDS on children. *Journal of child and adolescent mental health*, 16(1), 3-5.

Foster, G., & Williamson, J. (2000). A review of current literature on the impact of HIV/AIDS on children in Sub-Saharan Africa. *AIDS*, 14 (3), 275-284.

Furman, E. (1974). *A Child's parent dies: Studies in childhood bereavement*. London: Yale University Press.

Furks, S. I. (1998). Systems theory perspective and community psychology. *Journal of community psychology*, 26(3), 243-252.

Gillman, R.R., & Newman, B. S. (1996). Psychosocial concerns and strengths of women with HIV infection: An empirical study. *Families in society*, 77, 131-141.

Gray, M. L., & Grant, L.M. (1997). Orphaned children: A continuing problem in the HIV/AIDS epidemic. *Journal of HIV/AIDS prevention and education for adolescents and children*, 1(3), 137-149.

Grotevant, H. D., & Cooper, C. R. (1998). Individuality and connectedness in adolescent development. Review and prospects for research on identity, relationship, and context. In E. Skoe, & E. A. Von der Lippe (Eds.), *Personality Development in Adolescence: A cross national and life span perspective* (pp. 6-24). New York: Routledge.

Gringlas, M., & Weinraub, M. (1995). The more things change: Single parenting revisited. *Journal of family issues*, 16(1) 29-49.

Health Professions Council of South Africa. (2002). *Health professions council of South Africa: Ethical Code of professional conduct*. Pretoria: HPCSA.

Human Science Research Council (2005). *A literature review of evidence based intervention for home based child centered development*. Cape Town: HSRC Publishers.

Johnson-Moore, P., & Phillips, L. (1994). Black American communities: Coping with death. In B.O. Dane & C. Levine (Eds.), *AIDS and the new orphans: Coping with death* (101-120). Westport CT: Auburn House.

Kelly, K. (1992). Hermeneutics in action: empathy and interpretation in qualitative research. In M. Terre Blanche and K. Durrheim (Eds.), *Research in Practice: Applied Methods for the Social Sciences* (pp. 398-421). Cape Town: University of Cape Town Press.

Kelly, M.J. (1999). The response of the educational system to the needs of orphans and children affected by HIV/AIDS. In G. Foster, C. Levine, & J. Williamson (Eds.), *A generation at risk: The global impact of HIV/AIDS on orphans and vulnerable children*. (pp.141-150). New York: Cambridge University Press.

Land, H. (1994). AIDS and women of colour. *Families in society*, 75, 355-361.

Landman, C. (2002). The AIDS orphans of South Africa. *Contemporary Review*, 281(16), 268-270.

Levine, C. (2000). AIDS and a new generation of orphans. Is there a role for group care? *Residential treatment for children and youth*, 17(3), 105-120.

Lynch, G. (1997). The role of community and narrative in the work of the therapist: A post-modern theory of the therapist's engagement in the therapeutic process. *Counselling Psychology Quarterly*, 10(4), 353-363.

Maddi, S.R. (1996). *Personality Theories: A Comparative Analysis* (6th Edition). USA, California: Brooks/Cole publishing company.

Madhavan, S. (2004). Fosterage patterns in the age of AIDS. Continuity and Change. *Social Science and Medicine*, 58(7), 1443-1454.

Marcenko, M.D., & Samost, L. (1999). Living with HIV/AIDS: the voices of HIV positive mothers. *Social Work*, 44(1), 36.

Marcia, J.E. (1993). The ego identity status approach to ego identity. In J.E. Marcia, A.S. Waterman, D.R. Matteson, S.L. Archer, & J.L. Orlofsky (Eds.), *Ego Identity* (pp. 3-21). New York: Springer-Verlag.

Matheis, S., & Adams, G. R. (2004). Family climate and identity style during late adolescence. *Identity: International journal of theory and research*, 4(1), 77-95.

Makiwane, M. (2004, December). *The impact of HIV/AIDS on the elderly*. Paper presented at the meeting for child, youth and family development research programme. Pretoria: Human Science Research Council.

Medical Research Counsel (South Africa). (2005). HIV and informal settlements in South Africa. *Leadership in HIV/AIDS*, 16, 40-41.

Meyer, W.F. (1989). Freud's Psychoanalytic Theory. In W.F. Meyer, C. Moore, & H.G. Viljoen (Eds.), *Personality Theories: from Freud to Frankl* (pp. 41-71). Johannesburg: Lexicon Publishers.

Meyer, W.F. (1989). Erikson's Ego Psychological Theory. In. W.F. Meyer, C. Moore, & H.G. Viljoen (Eds.), *Personality Theories: From Freud to Frankl* (pp.145-165). Johannesburg: Lexicon Publishers.

Moore, C. (1989). Carl Rogers' Self Concept Theory. In W.F. Meyer, C. Moore, & H.G. Viljoen (Eds). *Personality Theories: From Freud to Frankl* (pp. 375-395). Johannesburg: Lexicon Publishers.

Moon, S.M., Dillion, D.R., & Sprenkle, D.H. (1990). Family therapy and qualitative research. *Journal of marital and family therapy*, 16(4), 357-373.

Monasch, R., & Boerma, T. (2004). Orphanhood and childcare patterns in Sub-Saharan Africa: An analysis of national surveys from 40 countries. *AIDS*, 18(2), 55- 65.

Mullis, R. L., Brailsford, J. C., & Mullis, A. K. (2003). Relations between identity formation and family characteristics among young adults. *Journal of family issues*, 24(8), 966-980.

Neuman, W. L. (1999). *Social research methods: Qualitative and quantitative approaches*. Needham heights: Allyn & Bacon.

Nielsen, L. (1996). *Adolescence: A Contemporary View* (3RD Edition). USA: Hartcourt Brace College Publishers.

Oliver, L., & Van Der Walt, H. S. (1996). Conveying test data to interested parties. In K. Owen, and J.J. Taljaard (Eds.), *Handbook for the use of psychological and scholastic tests of the HSRC* (pp. 139-153). Pretoria: Human Science Research Council.

Paige, C. Y., & Johnson, M. S. (2004). Caregivers' issues and AIDS orphans: Perspective from a social workers focus group. *Journal of the National Medicine Association*, 89(10), 684-688.

Payne, S. (2004). *Loss and bereavement*. USA: Open University Press.

Payne, S., Horn, S., & Relf, M. (1999). *Health Psychology: Loss and Bereavement*. USA, Philadelphia: Open University Press.

Parkes, C.M., & Weis, R.S. (1983). *Recovery from bereavement*. New York: Basic Books.

Papini, D.R., Sebby, R.A., & Clark, S. (1989). Affective quality of relations and adolescent identity exploration. *Adolescence*, 24, 457-466.

Pivnick, A., & Villegas, N. (2000). Resilience and Risk: Childhood and uncertainty in the AIDS epidemic. *Culture, Medicine and Psychiatry*, 24(1), 101-136.

Pharaoh, A. (2004). HIV/AIDS in Africa. UN issues warning on AIDS crises in Africa. *HIV Impact*, 14, 14-18.

Pharaoh, R., & Schonteich, M. (2003). AIDS, Security and Governance in Southern Africa: Exploring the impact. *Institute for security studies*, 65, 1-13.

Perosa, L.M., Perosa, S.L., & Tam, H.K. (1996). The contribution of family structure and differences to identity development in females. *Journal of youth and adolescence*, 25(6), 817-837.

Rajcoomar, U., & Roper, M. (2006). *Has the impact of HIV and AIDS affected the lives of rural gogo's?* Australia: Oxfam, Oxfam HIV/AIDS programs.

Rau, B. (2002). *Combating child labour and HIV/AIDS in Sub-Saharan Africa. A review of policies, programs and projects in South Africa, the United Republic of Tanzania and Zambia to identifying good practices.* USA: Department of Labour, International Labour Office.

Rees, S. (2004). AIDS orphans, the catastrophe revisited. *Societal Issues*, 6(2), 15.

Richter, L.J. (2004). *Family and community interventions for children affected by AIDS.* Cape Town: HSRC publishers.

Rutter, M. (1979). Protective factors in children's response to stress and disadvantage. In M. W. Kent, & J.E. Rolf (Eds), *Primary Prevention in Psychopathology* (pp.49-74). Hanover: University press of New England.

Sculthesis, D.P., & Blustein, D.L. (1994). Contribution of family relationship factors to the identity formation process. *Journal of counselling and development*, 73,159-166.

Siegal, K., & Gorey, E. (1994). Childhood bereavement due to parental death from AIDS. *Journal of developmental and behavioural paediatrics*, 15(3), 66-70.

Sishana, O. (2004). *The national household HIV prevalence and risk survey of South African children.* Pretoria: HSRC.

Simbayi, L.C. (2001). Health care seeking behaviour for sexually transmitted diseases in South Africa. *Journal of Psychology in Africa*, 10(2), 101-121.

Stroebe, M.S. (1993). Coping with bereavement: A review of the grief work hypothesis. *Journal of death and dying*, 26, 19-42.

Seely, J., & Kajurs, E. (1995). The extended family and support for people with AIDS in a rural population in South-West Uganda: A safety net with holes. *AIDS Care*, 5, 117-122.

Sherr, L. (1995). *Grief and AIDS*. Chichester: John Wiley and Sons publishers.

Statistics South Africa. (2005). *HIV and population census, South Africa*. Pretoria: Statistics South Africa.

Sullivan, K. & Sullivan, A. (1980). Adolescent- parent separation. *Developmental Psychology*, 16, 93-99.

Taylor, S.J., & Bogdan, R. (1984). *Introduction to Qualitative Research Methods: The search for meanings* (2nd Edition). New York: Wiley Inter-science Publication.

Telingator, C. J. (2004). Children, adolescents and families infected and affected by HIV and AIDS. *Child and adolescent psychiatric clinics of North America*, 9(2), 295-312.

Terre Blanche, M., & Durrheim, K. (1999). Histories of the present: Social science research in context. In M. Terre Blanche and K. Durrheim

(Eds.), *Research in Practice: Applied Methods for the Social Sciences* (pp. 1-16). Cape Town: University of Cape Town Press.

Terre Blanche, M., & Kelly, K. (1999). Interpretive Methods. In M. Terre Blanche and K. Durrheim (Eds.), *Research in Practice: Applied methods for the Social Sciences* (pp. 123- 146). Cape Town: University of Cape Town Press.

Tesch, R. (1990). *Qualitative Research: Analysis types and software tools*. New York: The Falmer Press.

UNAIDS & World Health Organisation (WHO) (2006, December). *AIDS Epidemic Update. 4th global report*. Geneva: Switzerland.

UNAIDS (2007). Report on the global AIDS epidemic. Geneva: Joint United Nations Programme on HIV/AIDS.

UNAIDS. (2008). *Report on the global AIDS epidemic update*. USA: New York.

Watson, M. F., & Protinsky, H. O. (1998). Black identity development: Effects of perceived family structure. *Family Relations*, 37(3), 288-292.

Webb, D. (2005). *HIV and AIDS in Africa*. London: Pluto.

Weiner, L.S. (1991). Women and human immunodeficiency virus: A historical and personal psychosocial perspective. *Social Work*, 36, 375-378.

Winston, C. A. (2003). African American grandmothers parenting. *Illness, crisis and loss*, 11(4), 350-361.

Worden, J.W. (1982). *Grief counselling and grief therapy: A handbook for the mental health professional*. New York: Springer publishers.

Worden, J.W. (1991). Grieving a loss from AIDS. *Hospice Journal*, 7, 143-150.

APPENDIX A: CONSENT FORM

PROPOSED MASTERS THESIS IN CLINICAL PSYCHOLOGY

THE PSYCHOSOCIAL EFFECTS OF AIDS AND THE DEVELOPMENT OF IDENTITY AMONGST AIDS ORPHANS BY BOITUMELO TSHENKENG

INFORMED CONSENT

The purpose of this study and my role in this study has been explained to me by the researcher, Boitumelo Tshenkeng.

It is my own choice to participate in this study.

I understand that my identity will remain confidential.

I have the right to withdraw from this study at any time for any reason.

.....

Participant

.....

Boitumelo Tshenkeng (Researcher)

APPENDIX B: RESEARCH INTERVIEW GUIDE

THE PSYCHOSOCIAL EFFECTS OF AIDS AND DEVELOPMENT OF IDENTITY AMONGST AIDS ORPHANS

Demographic Information

Name

Age

Level of education

Family Structure

Description of family composition

Birth order of siblings

Ages of family members

Level of education of family members

Breadwinner/ occupation/ profession

How did you know of your parent(s) health status?

Upon hearing it, how did you feel?

How was your relationship like before and after knowing their status?

How was it like when your parents started being seriously sick, did anything significantly change in your daily life? How did you feel?

How did the death of your parents impact on you, either emotionally, socially, financially, educationally or in any way significant for you?

How would you describe the support of your extended family after death of your parents? How did you feel about it?

How was growing up without parents like for you?

What do you miss the most about not having parents?

What are/were your greatest needs as a child growing up without parents?

How did you deal with the challenges you experienced as a child growing up without parents?

Did you feel different in any way from other children, growing up without parents? How?

Knowing that your parents were gone, how did you feel about the environment (family and community) you were raised in?

How do you think it played a role in who you are today

How would you describe yourself- the essence of who you are? How do you feel about it?

Is it how you would like to be or would you like to be different? How come?

How do you think your parents have played a role in who you are?

Would you say that growing up without parents affect the sense of who you are?

Do you feel anything positive or otherwise significant has come out of your experience?

